Qualitative Report produced to support the full Evaluation Report:

Altogether Better Working Together to Create Healthier People and Communities

Bringing citizens and services together in new conversations

Report produced by Dr Sue Hinder for Altogether Better July 2015





EXECUTIVE SUMMARY

In the qualitative evaluation we collected the views of 142 people. We interviewed health champions, stakeholders and practice staff. In each of the five practice projects we interviewed people from a practice which was doing well and a practice that experienced challenges in the eyes of the project leads.

The key findings were;

- Becoming a health champion is life changing for some people and life-improving for many.
- The changes were due to feeling more confident, having a purpose in life and making good friends. In some cases champions were feeling physically better. These changes were often achieved even where the health champion activities were not especially successful.
- Champions also said they enjoyed getting to know people from different backgrounds and cultures that they would not normally get to meet in their day to day life. Given that 1 in 7 of the population has been born abroad (ONS July 2015) this demonstrates the potential of health champion work to improve community cohesion.
- Although there have been many successes in the health champion work it has been more challenging than the Altogether Better team expected
- Recruitment was difficult and activities have been slower than expected to get off the ground
- The emphasis on achieving recruitment targets and organising training workshops meant that project teams were unable to give as much support as health champions felt they needed.
- All of the Practice Managers felt that the health champion work created more work for them than they had expected.
- Practice staff were not fully aware of all the health champion activities and there is an urgent need for each practice to establish robust feedback mechanisms in their practices to increase the visibility of the work.
- Receptionists potentially have a key role in the health champion work because they
 are on the frontline of the practice and have considerable knowledge of the patient
 population. They also have a key role in making the health champions feel welcome
 and part of the practice.
- The project leads discovered that organising work for health champions that helped the practice before their groups were established was a good way of starting the health champion work. It (a) familiarised the staff and the health champions with each other, (b) made the health champions feel useful and kept up their momentum for the work, (c) made the health champions and their work visible to patients and practice staff (d) the practice benefitted immediately from the health champions'

contribution, (e) it satisfied those champions who wanted to help the practice directly rather than set up groups, (f) it allowed time for health champions to gain confidence in the work.

- The practice staff, especially GPs, need to be made aware that 'hello' and a 'thank you' go a long way towards making health champions feel valued.
- Good relationships are essential for the success of the health champion work. Time needs to be spent on building those relationships.
- Health champion group activities are dynamic in nature; they are always work in progress and health champions need to be made aware of this to prevent disappointment.
- A key aim of the health champion work has been to change health services by providing more social activities for patients with non-clinical needs thereby reducing pressure on health services, and by integrating citizens into health service systems so they can inform the development of health services. The health champion work had not been going long enough to exert such 'system change' but there were early signs of this potential.
- There is no strong evidence as yet that becoming a health champion or participating
 in health champion activities reduces visits to GPs on a scale large enough to impact
 on health services but there is some anecdotal evidence from GPs which points to
 this possibility.
- There is evidence that the involvement of Young Health Champions in CCG policy making is making professionals 'think differently.'
- Sustainability of the health champion work takes many forms from funding by CCGs
 to health champions forming a charitable group to enable them to apply for small
 pots of funding.
- The Young Health Champion work has demonstrated a new model of volunteering that has the potential to contribute to the development of community resilience

A new model for the health champions' work in practices has been developed based on learning from the Altogether Better team and the evaluation. Early indications from the application of this model are very positive.

METHODS

Sample

Face to face in-depth interviews were undertaken with health champions, Practice Managers, GPs, receptionists and project leads involved in the health champion work. To provide a broad range of views and experiences the two practices were selected from each of the 5 project areas, plus the clinic based health champion work at a specialist service in the North East. Interviews were also carried out with Young Health Champions, stakeholders and project staff in the Shropshire Young Health Champion work. In Barnsley we interviewed health champions, stakeholders and project staff. In total we carried out 80 interviews gathering the views of 142 people.

In the practice based work, project leads were asked to select a practice that they thought was progressing well with the health champion work and one practice where they felt there were the most challenges. This provided a sample of ten practices plus the specialist service clinic.

Within each practice we interviewed

- One health champion who the project lead felt had benefitted the most from the health champion work
- A focus group of health champions
- The practice manager
- The GP most associated with the health champion work
- Receptionists (at least 2)

In the Barnsley and Shropshire projects 6 health champions and 6 stakeholders were interviewed. In Shropshire 3 of the youth workers were also interviewed. All 7 project leads were interviewed. The number, location and type of interviewee are found in Appendix 1. Interviews were carried out between January 2015 and May 2015. Interviews were recorded with the permission of the interviewee. Confidentiality was assured within the Altogether Better core team, that is, their views would not be made known to the practice or the project team.

Interview guides

Interview guides were developed by the Altogether Better core team based on their experience of the health champion work. The guides amended as the interviews revealed additional areas of interest. (Appendix 2)

Analysis

Interviews were fully transcribed and analysed using Computer Assisted Qualitative Data Analysis software. A Grounded Theory approach was used to analyse the data, that is, the data was not analysed with a particular 'lens', rather the data was analysed for themes emerging from the data itself. The Evaluation manager undertook the interviews and the analysis. To eliminate bias the transcripts and the coding framework were made available to the Altogether Better core team and the Innovation Hub. The final qualitative evaluation findings were also checked for resonance with their knowledge and experience of the health champion work.

HEALTH CHAMPIONS BENEFIT

Life changing

There are some champions that feel that health champion work has had a major impact on their lives.

"It's really helped me get back on track,... because when they did the induction, it was all about isolated and lonely people, well I was one of them isolated and lonely people, so basically left to rot.... and literally that text that (project worker) sent that day, saved my life." (Calderdale, health champion)

"After this bereavement I had, not having a job, not having a purpose, I started having panic attacks a couple of years ago, quite bad and I'm still having them a bit but because I'm having to go out and be the centre for people and there for people and responsible, it's really helped me....this has helped me more than any medication might." (Calderdale, health champion)

Confidence

Many champions said they had gained confidence as a result of becoming a health champion.

"I've definitely got to know more people, obviously it's given me more experience in different things and it's made me more confident. Whenever I get an email or a text message through saying that there's an event or something going on, I would always push myself now to go and you just never know who you might meet or what opportunities might come up, so it's definitely made me more confident." (Bradford, health champion)

"I also find that because I've come back into something that has to push my boundaries because for years, I didn't do anything out at the front; that's given me a bit more confidence to speak to people." (Sheffield, health champion)

"I think it's made me more outgoing. If I'm fighting for somebody else, I'm all right, if I'm fighting for myself it's a different matter but for somebody else, it's good and I don't mind putting myself out for somebody else." (North East, health champion)

One health champion, a new immigrant, felt being a health champion helped her integration into the community as well as making her feel better

"I feel positive and like give me energy ... You feel you are not out of place, you feel there is somebody with you, speak with you, or do something together." (North East, health champion 2)

Another health champion's confidence and self-esteem was increased when she was asked to become a member of the PPG as a result of her health champion work.

"I lived on the council estate just across there and to think that now I'm 60, that one day I'd be asked to join the PPG is just amazing so that has been, that took my breath away." (East Riding, health champion)

Having a purpose

Some of the health champions were previously isolated and now have more friends, get out of the house, and have something to 'get up for'.

"I'm not sat at home with a cat and a bottle of wine". (Calderdale, focus group)

One health champion said he had hardly been out of the house for 29 years.

"Well it gets me out of the house. I can sit on my own at home quite happily, sit reading or sit doing nothing. It's getting me out a bit." (Calderdale, focus group)

"I enjoy it and my daughter said 'It gets you out Mum and you're around people your own age". Cheeky madam!" (East Riding, health champion)

Community

One health champion believed that the health champion work had the potential to restore a sense of community to the area.

"I think it's just a damned good thing for the community. I just hope it all spins off and more people join us and we feel more of a community." (Calderdale, focus group)

One champion commented that she now knew people to say hello to when she was out in the local area and how that improved her sense of well-being.

"It's nice to also have other...friends in the community, that when you go out, you see people you can say hello to and it just gives you a little boost, or a big boost." (Sheffield, focus group)

Feeling Physically Better

Some champions said they are feeling better physically as the result of becoming a health champion.

"It's two years now I've not been to hospital for a check-up because I feel healthy, everything fine, so these sorts of things help people." (Sheffield, focus group)

"I've got fibromyalgia and some days it can be very debilitating, you can't get out of bed but I do, I make myself and yes, I come for my repeat prescriptions but I've not been for ages to the doctor." (Sheffield, health champion)

"I help to run the craft group with Norma and still do the walking and then S does Somali dancing, so I joined that, so I'm getting plenty of exercise!" (Sheffield, focus group)

"I made friends with N and her sister and they teach me language, so it's given me a chance to meet people and just get out of myself, from a health perspective it's marvellous for me!" (Sheffield, focus group)

GPs notice a difference

Some GPs had noticed a difference in their patients who had become health champions. Although these are isolated incidences at this stage in the project, they prove the potential of the health champion work to have a major impact on people's lives.

"I'd got a retired English teacher whose now involved with the teachingit's given her another meaning because she was very depressed and it's given her a meaningful life...... Yes, she's had other problems going on but they were sorted out as well, so it's not fair to say it's all just because of that but yes, I see her a lot less." (Sheffield, GP)

"Yes, I can think of a particular person, she's slimmer, she's more confident, she's more confident in the way she relates to us in the consultation. She used to be deferential and she's more self-confident now." (Bradford, GP)

"I think there have definitely been, I can think of one person in particular where there's definitely been benefits in socialising and a person that was new to the area and this was a way of them making friends and meeting up with people and getting involved." (North East, GP)

Practice staff notice a difference

In some cases the benefits for health champions are noticed by practice staff

"She was quite a reserved person, wouldn't speak, I've known her for a long, long time and your mum and dad who are sadly not here anymore, and I noticed quite a big difference over the years with this girl and she was continually coming here because of the problems she had. Now she can stand up and talk, she gave a talk at the Royal Station Hotel on what the champions were about, she has stepped into the role of being our caterer and she produced a beautiful spread for the tea dance, the cakes were absolutely beautiful, they really were." (North East, receptionist)

"He's like a really valuable member of the group, he's got lots of ideas and if you see him in the corridor now, he's like "Hello!". He's just a completely different person." (Calderdale, Operations Manager)

"I can think of one person who I know this has helped a lot, doing the patient champions because it's got that person out more and she was always saying how much of an advantage it's been for her." (Calderdale Receptionist)

"I think for a lot of them it's given them purpose again because maybe some of them, when they initially started the group, did not have purpose because they had busy jobs and then you go into retirement and I think for some of them, it's got them involved in the community." (East Riding, practice manager)

Enjoying Diversity

Many health champions mentioned that they enjoyed the opportunity the health champion work gave them to make friends with people they wouldn't normally meet in their day to day lives. This may be people of different ethnic origins or different age groups or both.

"Meeting different people and different cultures and the health champions, I admire them for wanting to come and help out in a project like this and they've only been in the country for a short time." (North East, health champion)

"And I like it because we're such a mixed bunch aren't we? No we've got everything. You know we've got youth......Yeah a couple of young lads, a couple of young lasses. There's Jolene and Jasmine, all sorts. There's a range of ages. Most of us are either knackered or retired." (Calderdale, focus group)

"Me and Khadija, she's only 21, we're on the desk on Fridays and we bonded... she looks at me as though I'm her grandma, she says I'm her adopted grandma and we do get on and it's nice, she speaks very good English and she can speak bits of language and she'll help, we get by" (Sheffield, focus group)

"Yes, the Asian men being on the desk together with the older English women and that sort of chattering that you wouldn't normally get." (Sheffield, GP)

"Me and Maureen have hit it off and some of the Asian girls, we have, the younger Asian ones, one of them we've made friends with, she's expecting a baby any minute but she come straight to me and Maureen to tell us, she's Indian." (Sheffield, focus group)

"Well what I like about it (face book group) is that it seems to be attracting people from different nationalities, like immigrants and that, we've got different, you can tell by their names they're... Maybe that's another social thing that it could bring like ethnic groups together type thing." (North East, focus group)

Enjoying additional training courses and support

Many of the champions have attended different training course as a result of being a health champion. Sometimes these are related to health champion activities, such as Walk Leader training or Read Aloud training. Some courses are not always related to being a health champion but have been made available by the host organisation. Health champions have appreciated the opportunity of attending the courses.

"But like I say, the actual Altogether Better thing has, like I say got onto like allotments and things, got an allotment out of it. ...because I went along to one of the South West Yorkshire Partnership days for gardening, for mental health." (Calderdale, health champion)

"I've been on about six; I've got the certificates at home. Some mental awareness, wellbeing, I just forget what they are now, but I've been on about six." (Calderdale, focus group)

"Smoking Interventions, I did that and when they did the Stoptober, I came into the surgery to kind of promote that." (Calderdale, focus group)

"There's first day training which the Ambulance Service are providing because a number of champions wanted to do that, I think about 15 of them have come forward saying they want to do that." (North East, Project Lead)

Sometimes the training is in the form of one-to-one support.

"With the craft group, we're introducing it now that the tutor's going to help every second session, so the people in the group, we've been building their confidence to lead the sessions because they're very quiet people and they're not very directive, so we've been supporting them so that they can learn to lead a sewing and knitting session once a month." (Sheffield, project worker)

"I did training with Rachel on befriending with (name) Clinic...So it's like providing support one to one, so I'm doing that." (Sheffield, focus group)

A bridge into work

Being a health champion can help people to make the transition to work or voluntary. One health champion found that the caring values of the health champion work helped him to get a job in the NHS. Another found the experience of being a health champion helped her get a job as a health trainer.

"It's made a big change in my life. I applied for the health trainer training twice before, not successful and then I applied for it again a third time and with all this experience behind me now, thankfully I got through and I'm now working as a health trainer as well." (Bradford, Health champion)

Being a health champion had given one person hope that she could one day get back into work.

"Doing the pain support group and then going into having the option to do something like massaging and doing a day course and getting a qualification, it has made me think that I want, I've always wanted to go back to work, but if I can do the training and retain the information, it will be better for me." (Sheffield, health champion)

Friendship and socialising

An important part of becoming a health champion is making new friends based around a common interest – helping others. Sometimes this is a close and supportive group in the practice and sometimes the friendships develop into meeting outside the health champion work. One person said that being in the health champion group was like having a new family.

"I've met some really nice people, which is actually quite humbling because it's people who are in the same position to me, better than me, worse than me." (specialist service, health champion)

"I've met you haven't I, love?! I made a friend." (Bradford, health champion)

"We're very close, the two of us and through the Calderdale Forum, eventually we got to the idea of let's get together, so we get together one a month down at the pub, unofficial, we call it a social whereby members from (another practice) - all champions - and from here and anybody's welcome." (Calderdale, focus group)

"Wandering about that park crying,... just crying and I was lost. So people were really good, and looked after me." (Calderdale, focus group)

HC1: "Well, to be honest the biggest benefit that I've found is, I've made a new social circle of friends, really nice friends."

HC2: "New family, yeah."

HC3: "Yeah, really good friends and we're a good team and we support each other and it's a good laugh. We have social, we don't meet socially outside but we really are good mates and we're a good team." (North East, focus group)

"It's got me out of myself and I've made friends with different people and talked to different people and been more sociable." (Sheffield, health champion)

"At the time my little dog got killed and I needed something to keep myself going so I went to this (health champion) meeting and I hit it off with Shirley straight away, and I just talked to Keith for an hour because he's an animal lover, and I felt tons better." (East Riding, health champion)

"I've made two fantastic friends." (East Riding, health champion)

PATIENTS BENEFIT

There are many examples of health champions, practice staff and GPs noticing the improvement in well-being of patients who have attended health champion activities.

Health Champions notice a difference

Health champions at one practice (Bradford) had noticed significant changes in the well-being of four of the people attending Arts and Craft group held at the practice. They gave the example of the changes they had seen in two of them.

"A lady, who lived on her own, was very lonely, from (town), her dog had just died and she was bereft and she was unwell, she'd had a cataract removed and she was lonely. Another lady had had nose reconstruction...she felt so self-conscious....These people now, four months down the line, have absolutely blossomed and when you come along to the craft group now...the difference in them is amazing, they've grown in confidence with each other."

These ladies had also started going out with each other socially since they had met at the Arts and Crafts group. Another lady who attended the group after her husband had received a diagnosis of a life-threatening illness told the project workers that attending the group had been 'life-saving'.

Another health champion (Calderdale) noted the benefits in people attending her Relaxation Group and felt that, in the case of one lady, this was associated with people feeling comfortable enough to share their mental health problems with others in the group who had experienced something similar.

"One lady had agoraphobia for a long time and she managed to get there and she loves it, she brought her friend and then we've got another lady who is very quiet and she managed to get herself there and I think what's happened is because some people had disclosed some of the things that have happened to them and why they've been depressed etc., she's realised that her things aren't just as serious and she seems to have come out of herself quite a lot." (Calderdale, health champion)

At one practice (Sheffield) the health champions run a Women Only Support Group which is for women who have experienced domestic violence. The champions don't focus on domestic violence, they provide other craft and cooking activities for the women to enjoy. They can provide information on other services if the women need them, or talk about their problems. The health champions measured their success in smiles on faces.

"At first they're quite anxious, like nervous and all that but it's when they leave the group, it's the smile what they have on their faces because they didn't expect it. They don't talk about the abuse because that's not what we're about, if they want to, they can take us to one side and talk about it but what we do is we have other activities going on." (Sheffield, focus group)

Practice staff notice a difference

One practice manager, (Calderdale) was convinced of the huge potential of the health champion activities from one example mentioned to him by a GP.

"A young girl came in to see my diabetic lead the next week and went, "That diabetes meeting has changed my life totally because I wasn't managing it properly, I met all these people who have been doing it for years and it's already changed my life." (Calderdale, Practice Manager)

The Reception Manager at one practice (Sheffield) was also aware of one gentleman who had improved his well-being with the help of the health champions.

"He's a diabetic patient and we'd always struggled with his weight management, he was referred onto a weight programme, worked wonders, diabetes is more under control now, he feels so much better, he can't praise the work that the practice champions and everybody like that has done around that." (Sheffield, Reception Manager)

One of the most adventurous and generous health champion activities had a huge impact on patients at the time and beyond. The practice manager and health champions organised a Christmas Day meal for 18 people who were isolated and would have been on their own on Christmas Day. Food was donated by organisations and cooked by a health champion. The occasion was enjoyed by patients and health champions alike and for one person led to longer term benefits.

"On Christmas Day, we held a Christmas dinner for isolated patients and we had a refugee family who used to use casualty as their default for care provision, they came along and had Christmas dinner and had a lovely time. Another lady came along who isn't a patient in the practice but who was referred to us by Age UK. When I went to visit that lady, she said to me, "I just want to get out of the house for one hour a week" and she's now out doing four different events every week." (North East, Practice Manager)

GPs notice a difference

Some GPs have noticed an improvement in the well-being of patients.

"I think there have definitely been, I can think of one person in particular where there's definitely been benefits in socialising and a person that was new to the area and this was a way of them making friends and meeting up with people and getting involved." (North East GP)

At this practice, the manager also goes out with the Walking Group and she has noticed similar beneficial changes in at least two other participants.

One GP who occasionally went out with the Walking Group noticed a difference in a participant's well-being, not only physically but also in confidence levels.

"Yes, I can think of a particular person, she's slimmer, she's more confident, she's more confident in the way she relates to us in the consultation. She used to be deferential and she's more self-confident now." (Bradford, GP)

Sometimes it's difficult for GPs to attribute increased well-being in patients and less GP visits to involvement in the health champion activities but there seems to be a correlation.

"Yes, she's had other problems going on but they sorted out as well so it's not fair to say it's all just because of that but yes, I see her a lot less, it's just a phone call when she said "I'm coming in anyway to the Christmas Party", she wasn't coming to see me. That's great." (Sheffield, GP)

In one practice where the practice manager has been very proactive in supporting the health champions, the GP definitely did notice the impact on patients.

"I must admit it's been fascinating, it's been really interesting...my patients who used to see me frequently, now don't see me as much because they have that support network. It's mainly mental health patients and mental health problems... and they've got roles, they're taking responsibility as well." (North East, GP)

The GP noted the example of one patient who joined the Reading Group at the practice and has since gone on to do voluntary work and is now looking for employment.

Health Champions promote healthy behaviours

Some health champions are directly involved in promoting healthy behaviours. One health champion (Sheffield) gave the example of a friend she encouraged to go for breast screening who had thought she was too old for the screening. The lady did, in fact, have a tumour that would have been difficult to spot herself. She was treated successfully. Another health champion from the South Asian community encouraged his wife to go out and join the walking group with her friends to overcome her low mood. She now regularly attends activities with her friends and feels much better. At the same practice the health champions helped with interpretation at a Diabetes information session organised by a GP. The event was an 'eye opener' for the GP who discovered that some people did not know what diabetes was, despite having the condition for several years.

The health champions at one practice (Sheffield) in a community with recently arrived immigrants and a great deal of community tension were able to help patients find appropriate services, especially dental services. Due to their lack of knowledge about the English health system they had been coming to the surgery or A&E with dental problems.

"They don't know where to go when they got toothache so they weren't registered with the dentist, so they have to go to emergency, so medical centre was struggling. So we managed to refer them, we had a training here about our dentist practice and we've been referring them and telling them where they need to go and where they can register." (Sheffield, focus group)

One practice (North East) also organised a self-care health event around a tea dance which patients had said was an activity they would like to see provided. It was attended by over 200 people, far more than would ordinarily attend a self-care health event.

"So they were invited to a tea dance but the premise running underneath that was about engaging people in self-care but you know, we had somebody who baked cakes for diabetes patients and she had recipe cards that we were able to share, but Arthritis Care were there, so they could provide information about, "You're not able to dance very well today because you've got a sore toe, this is all the other stuff that we can provide for you". (North East, Practice Manager)

Practice staff see the patient's need

The receptionists can have an important role in the development of the health champion work. One receptionist at a practice where many patients don't speak English asked if the health champions could put on an English language Conversation Club for patients they struggled to understand at the reception desk. The health champions did provide the club and the receptionists noticed a significant difference in some of the people who attended. The Club provided an informal environment to learn English rather than a formal classroom situation.

"There's one patient in particular, a Slovak man that could speak absolutely no English, we encouraged him to go to the conversation club and he has, not brilliantly but he has picked up some English which has obviously helped him with us and with other services out there, which is great." (Sheffield, Reception Manager)

Another receptionist offered the health champion activities to one lady who told them she was lonely.

"We referred a lady that's on her own, that's very lonely, she came into the practice about 8/9 weeks ago, stood at the front desk talking to my receptionist and she was so low and so upset and she just said, "I just feel so lonely", so we referred her onto Sheffield Wellbeing and the practice champions. She's now going on the walking clubs every week, a bit of socialising and she said "It's made me feel so much better" and we've noticed a significant difference in how much she's contacting the practice since doing that... Even the receptionist said, "I can't believe the turnaround in her in six weeks", it's brilliant." (Sheffield, Reception Manager)

SYSTEM CHANGE (OUTCOME 2)

Reducing GP appointments

There is some anecdotal evidence of reduced GP visits where a patient has become a health champion or a participant. Although this is not strong evidence of the health champion work reducing GP workload, it does provide 'proof of concept' that it has the potential to do this, as well as improving the well-being of champions and those who attend health champion activities.

"I've noticed a significant drop in her phone calls and attendance at the surgery, which is exactly what we want." (Sheffield, Reception Manager)

"We don't see her anymore, the GP keeps saying to me, "I haven't seen such and such for a long time" and I keep saying, "Because she's too busy doing things for me to come and see you"! There are so many stories like that that we can tell, through people becoming practice champions but also then people going to the groups that the practice champions have set up." (North East, Practice Manager)

Staffing the health champion work

The fact that most practices want to fund the health champion work is an indicator of how much they value the work and believe in its potential to improve care for patients. However, some practices felt that they wouldn't be able to continue the work without further funding. Ironically this view was more prevalent in practices where there had been the most health champion activity.

In one practice (Bradford) a Health Education officer was employed and part of her remit was to support the health champion work. The health champions found this support invaluable and the practice manager felt that the work could not continue without further funding of this post.

One practice (Calderdale) was appointing another manager within the practice and supporting the health champion work was to be part of their remit.

Another practice (North East) obtained was applying for funds to support the health champion work.

"I've just sent an email out to anybody and everybody who I could think of, where there might be some end of year money that's available to help us to test theory because it's new and it's early days for us and it's about general practice doing things differently." (North East, Practice Manager)

They were eventually successful in finding funding to employ one of the project team 2 days a week.

In East Riding the project team have encouraged practices to appoint a health champion liaison lead. This is a receptionist because they know both the champions and the patients and are more readily available to speak to champions than the practice manager.

Providing space in the practice for the health champions

Providing space for health champions within the practice is another indicator of how the practices value the health champion work and its potential to change the nature of the work of the GP practice.

One large practice (Bradford) in a new building with sufficient space allowed the health champions to use rooms within the practice for their meetings and activities.

Some smaller practices (Calderdale, Bradford) offered rooms for the champions but on a more restricted basis, on certain days of the week.

Some practices (Sheffield) were considering creating space for the champions to work from.

"It's just sitting, waiting area that's opposite the reception but there's a small room, they're thinking to change that to, for practice champions." (Sheffield, focus group champion)

Some practices (Calderdale, East Riding) have included space for the champions in their plans for extending or redesigning the practice.

"As part of our plans for an extension that we're putting in and discussing with NHS England at the minute, is to have a community room with a kitchen area for the purpose of things like these groups - because then anyone can turn up and say, "I want a group", providing we agree with it, but they can potentially get patients from the waiting room and say, "After you've had your appointment with the doctor, we've got this group on today if you fancy popping along". (East Riding, Practice Manager)

Health champions are seen as part of the practice

Another indicator of the health champion work changing the GP practice is how the practice staff view the champions and include them in practice activities.

"They've just become part of the practice, they're not an add-on, they're not different, they just come along, they have a cup of tea, we decide we're going to do things and we do them together." (North East, Practice Manager)

One practice (Bradford) has invited the champions to the annual all day training event they have for their staff at Christmas time. Also the practice manager invites health champions to be present when they have visitors to the practice.

At the specialist service clinic the health champions played a critical role shaping clinic services and a health champion was invited to take part in a clinic 'away day' arranged to discuss the future of the clinic.

"(We have) gone through a very rigorous research process called concept mapping, with lots of people who have been to the clinic, ranking and prioritising what they wanted out of the clinic and then we've reviewed all of that with the champions, so they may or may not realise this but they've got a very critical role in shaping what the clinic delivers." (specialist service, Clinical Lead)

One practice was investigating the possibility of having a health champion regularly behind the reception desk.

"We are looking into having a volunteer behind reception as a bit of a presence but that needs a bit more looking into and thinking through, so that it's done properly and we have the right volunteer, reliable volunteer behind the reception desk, so they'll be more of a frontline presence, rather than sat on the enquiry desk in a separate area, they'll actually be on the desk." (Sheffield, project worker)

Health champions in another practice (East Riding) were well established in their role of collecting the Family and Friends questionnaire on tablets.

"That's a totally practice and champion initiative now because we don't have any involvement in it, the champions, there's a champion who takes the lead on that and he does the rota, so once a month he'll contact all the champions and get them to put their names down." (East Riding, Project worker)

Practice staff offering health champion activities to patients

Both GPs and receptionists have been able to offer health champion activities to patients they think will benefit from them. One receptionist said it made them feel more 'professional'.

"It's made us look a lot more professional in a way because not every practice can offer support groups for different types of things, like when people ask you normally you'd say "look on the internet" or something, but we can point them to our champions." (Calderdale, Receptionist)

Health champions expand the options available for patients

The health champions can offer activities that currently GP practices don't or can't or maybe just find difficult to do, such as Arts and Craft groups, Walking groups, Knit and Natter groups and Women's Support group. (See Activities)

"We're creative people aren't we, and we think outside the box. Where the people in here, they're a bit more constrained and we can do things that they can't do, and they couldn't justify doing because the people who pay their wages say you cannot do that, but we can do it and they can support us." (North East, focus group)

Promoting prevention and self-care

The health champion work offers practices more opportunity to promote prevention of health conditions and self- management of long term conditions.

At one practice (North East) a Tea Dance organised by the practice manager and health champions 'disguised' the self-care event and attracted over 200 people, more than would normally have attended such an event.

"So they were invited to a Tea Dance but the premise running underneath that was about engaging people in self-care but you know, we had somebody who baked cake for diabetes patients and she had recipe cards that we were able to share, but Arthritis Care were there, so they could provide information about, "You're not able to dance very well today because you've got a sore toe, this is all the other stuff that we can provide for you." (North East, Practice Manager)

The health champions also promote the services offered by the practice and health information.

"Promoting health issues and things that are going on within the practice, helping us to have the link between the patients and us because that can be a problem sometimes." (Sheffield, Reception Manager)

"...and you get these champions eventually, 'teched up' with everything that we do as a practice, then when they're discussing things with patients, they can say "Why don't you do this?", and then you've got experts in the practice who can help patients use the services to their full potential because more often than not, gripes and grumbles, they're not always about the way we actually do things, they're more often than not, they don't realise we can do something differently." (East Riding, Practice Manager)

The health champion work can also change the image of a GP practice as one for wellness as well as illness.

"There's other things happen at your doctors, you don't have to be ill to go, you can go and join a group, you can go and meet people, you can go and have a cup of coffee." (North East, focus group)

Working with the PPG

In some instances the practice manager decided to create a link between the PPG and the health champion work. In one practice (Bradford) the practice manager has found that the health champions make a valuable contribution towards patient engagement within the practice and has made every third PPG meeting a joint one with health champions.

In the case of another practice (East Riding) the practice manager has invited two health champions to become members of the PPG.

Creating practice links with the community

In the case of one practice, the health champion work has increased and strengthened the practice's links with groups in the community giving the GPs more information on what's available for their patients.

"There was one woman who was walking a dog, she was from Age UK, she wasn't a patient in the practice but she went away and came back with her badge on and she spent the afternoon with us and as a result of that, this week, we have an Age UK primary care navigator starting in the practice, who's going to work with us on social prescribing and I just think that's the power of practice champions in terms of engaging, making those links and things." (North East, Practice Manager)

"..and I think that's improved, with the patient champion group, we've become more aware that we can offer services like that." (North East GP)

Reducing the receptionist's workload

Health champions at some practices (Sheffield, Bradford) have helped patients to use the electronic sign in process receptionists have noticed a difference in their work load.

"Volunteers showing people how to book their appointments online, they have noticed that the amount of people booking their appointments online has increased, slowly but it's getting there." (Sheffield, project worker)

PRACTICE MANAGERS' EXPERIENCE OF THE HEALTH CHAMPION WORK

Motivation for getting involved

The practices were generally thinking of ways to increase patient engagement in their practice when they were introduced to the health champion work.

"Because we've had really good success with our PPG, we thought it was a really good project that Humber were trying to put in place, with involving patients of delivering of services and looking at groups to set up. We thought we had a place for them in the practice because there are a lot of patients who come to us and want to be involved in other things." (East Riding, practice manager)

"We had already decided... that we wanted to try to set up a walking group ... because all things patient engagement are very new to me, it's felt reassuring to have something like the health champions, to have the support really of the health champions organisation to help us move that along." (North East, practice manager)

"There were ways in which working with volunteers would be quite useful, from supporting patients with becoming more healthy and managing their own health more effectively, to perhaps helping us in the practice, ...So there's a range of things and I'd thought about it and then I heard about the Practice Health Champions and so I pursued that." (Bradford, Practice manager)

"We kind of saw it as making us a community hub." (Calderdale, practice manager)

"I think that's what I mean, our motivators aren't around what the practice gets paid to do, our motivators are around what is it our community want of us?" (North East, practice manager)

Practice Managers' expectations

All of the Practice Managers felt that having health champions in the practice was more work than they expected. All Practice Managers felt supportive of the work in principle but most felt they didn't have the time to be fully involved in attending meetings.

"So it's sometimes very difficult to lift your head up and see what's happening and be involved in every meeting because that's not doable." (Sheffield, practice manager)

"I suppose initially, we were told that it wouldn't really involve us but it does. You can't get away from that because ...Just liaising, you have to be involved, meetings

that take up time, organising anything in the practice, telling the staff about it, getting people on board." (Bradford, practice manager)

Most of the Practice Managers were also disappointed that the health champion work seemed slow to progress.

In two of the practices the health champion work had exceeded the practice manager's expectations.

"Yes, in some ways I'm very pleasantly surprised, we've now trained forty-four Practice Health Champions and we've got thirty that are active... So that's quite good and it's evolving quite rapidly." (Bradford, practice manager)

"The work that we've done in the practice has far, far exceeded my expectations in terms of the skills that they've brought, the enthusiasm, the time they've given, actually how they've just become part of the practice." (North East, practice manager)

One practice manager (Calderdale) was disappointed with the people recruited as champions; he felt there should have been a vetting process. He was also disappointed that they did not seem to have ideas for activities or their ideas seemed unrealistic to him, such as a long community bike ride.

Some Practice Managers were a little disappointed that health champions were not interested in some of the 'jobs' that they felt would have been helpful for the practice.

"We've got a self-assessment area so the idea is you take your blood pressure, your height, your weight, you then get your BMI and then you put it on a little form... we put you on a register and treat you and manage your condition. So we wanted them to host that area, they've not done that." (Calderdale, practice manager)

"But that would have been so valuable to us. So there does seem to be a little bit of a tension between this sort of co-design and things that would really help the practice, aren't always the same thing." (Bradford, Practice Manager)

"What happens is, two said that they were going to do that and then they didn't turn up. You get ones that are really good, reliable and then you get ones that say they're going to do stuff and don't, so that tarnishes the credibility in terms of commitment." (Bradford, Practice Manager)

Practice Managers' knowledge of health champion activities

Most Practice Managers had a general idea of the health champion activities in their practice but some were not fully up to date. In one practice the practice manager was fully involved and even initiating and taking part in activities.

"(Practice manager) got up and did a Bollywood dance, she was very good! We all stood, mouths agape, that this person was up on the stage, it was really good, it was lovely!" (North East, receptionist)

In most practices little thought had been given to communications between the health champions and the practice. (see 'Feedback Mechanisms', P.43)

Relationships with the health champions

Good relationships between practice staff and health champions are key to the success of the health champion work.

In some practices there were 'teething problems' in the relationship between the practice staff and the health champions, such as concerns about patient confidentiality and protected staff space.

"People were a bit ... about them coming up here into this space and it was "It's confidential" and it's like ... "they've signed the same thing as what you've signed" but then the staff feel that certain space, they want just to chill out, like the staff room." (Bradford, practice manager)

Although the practice manager herself didn't have a problem with the health champions going to the staff rest area, she felt she had to ask the health champions to stay down stairs and use the kettle in the office.

"At the end of the session, E (health promotion officer) was approached by the head caretaker to say that there'd been a complaint by the staff about the practice champions pinching the hot water for their tea and we were not to do it again." (Bradford, focus group)

The practice manager solved this situation by asking the health champions not to be in the kitchen at staff break times and supplying them with hot water flasks for the seminar room where they met.

The relationship between practice staff and health champions takes time to develop; people get to know each other and understand their roles.

"Yes, the relationship has improved from patient/user to "hi, have you come from a meeting? What are you here for today?" (Bradford, focus group)

Health champions perception of practice staff

Despite the reported enthusiasm of the Practice Managers for the health champion work, the health champions often felt that the practice did not fully support or appreciate the work they did or were trying to do.

"But members of the practice haven't been attending our groups at all, the doctors were really in favour of it and they would be coming to meetings and encouraging us but sometimes we've had a meeting and they've said Dr So & So will be coming to the meeting, and it never happened." (East Riding, focus group)

"We've had issues that we've actually felt on our own, that we come and we're on our own but I think that that has been worked on now and I think (project worker) has done a lot to try and make it so that when we come into help them here, they know we're coming, our tablets are charged, if we don't have a password, they know how to sort it." (East Riding, focus group)

"But we do find them really useful and we've found them a really good resource. They've just been brilliant with helping us with some of the stuff in the surgery." (East Riding, practice manager)

An operations manager, with close involvement with the champions felt the staff enthusiasm for the work created a good relationship with the champions but the health champions still felt there was a lack of support from the surgery.

"I think we ourselves have all been enthusiastic about it, we haven't been "Oh we've got to do this, let's go and meet the patients", it's been "oh yeah, this is going to be good, we'll go and see what's going on", I think that helps." (Calderdale, operations manager)

"I think we felt as a group that we weren't getting a lot of support from the surgery." (Calderdale, focus group)

Different champions sometimes had different views of the same practice.

"Well, I'm not entirely sure ... a couple of doctors know who I am but I don't think too many people know that I'm a health champion, to be honest." (North East, health champion)

"As Health Champions we're valued as well. We don't feel as if we're a separate entity, we are part of the team." (North East, focus group)

In the case of one practice where the practice manager was very elusive to the project team and was not available for interview, the champions found her very welcoming and approachable.

"It's been quite difficult. I think they wanted to get practice champions because it was such a busy practice and they really needed that help but then they've kind of not had the time to focus on the project themselves." (Sheffield, project worker)

"I've been in contact with (practice manager) face to face, she's quite supporting, she always welcomes us anyway, asks us if there any questions, if there's anything that

we need and yes, so there is a great collaboration actually between us and her as a manager. She's great; it makes us feel important anyway!" (Sheffield, focus group)

It seems that 'perceptions' on the relationships between practice staff and health champions do not always coincide.

Project teams promote practice and health champion relationships

Project staff have taken on board the importance of nurturing the relationship between the practice staff and the health champions and have developed the work to include more prework with the practice.

"When you're going to foster a child into a family, you make sure the entire family know, I don't think we have, we haven't let the reception admin staff know. They just turn up one day and it's "Oh these are the champions by the way." (North East, project lead)

"So we need the practice manager, the practice staff to fully understand what it is so even if that takes us working in the practice for a number of weeks before it even starts... so when the champions start walking through the practice door, everyone in the practice knows who they are and what they're about." (East Riding, project worker)

"Who is it that those champions respect? They respect the GPs and the GPs need to be there and even if it's for 10-15 minutes just to say "Hi, thank you very much for what you're doing, we really appreciate it", it takes minutes but that for them will mean the world and if the practice can't offer that, then we've got a problem." (East Riding, project lead)

"We've had to work on building those relationships between the GP and the community organisation that were recruited, so we've had to build those relationships up as well as the champions having to build the relationships with the host and the GP and then with me!" (Sheffield, project lead)

Practice Relationship with the project team

All the Practice Managers said they had a good relationship with their project teams and expressed their gratitude.

"E was there at the beginning, fantastic, very approachable and she had really good knowledge of working with patient groups and voluntary organisations and she was really good. G's been fantastic but he had a lot to learn when he came on, but I just feel that during the work week, as a busy practice manager, we get a lot of emails asking about things, clarification on things. R knows what he's doing but you've got

these two people who are permanently emailing you about different things and I just wonder if ... there's other ways." (East Riding, practice manager)

"P and M are great, fantastic, they've come in and done their meetings, I think it was planned monthly but I don't think we've managed to get monthly but I think that's just because of other work that everybody's had on. But yeah, they've been great. I think P is absolutely fantastic, I think the champions rely on her very heavily for things and I think she deals with that really well." (Calderdale)

"I think there are days that G comes in here and we're really heavy in terms of, that we've got to do this and we've got to do that...and G comes in and she just adds an air of lightness and just cheers us all up. That to me is really helpful but she's been a key catalyst in making this happen." (North East, practice manager)

Changing the practice ethos

The Practice Managers reported signs that the health champions were beginning to change the ethos of the practice from one in which the practice provide a clinical service to one in which health and well-being is created jointly with the patients.

"I like it. I think it brings a new dimension to the practice and I think it will take a while for it to sort of bed in and get comfortable and to be reasonably well accepted. I'm delighted that we've got 30 who are active, I think that's fantastic, they sort of come and go a bit, they go off and they do their own thing for a bit and then they come back but that's fine." (Bradford practice, practice manager)

"Reception are very aware that what we're trying to do, that we're trying to establish a relationship, a different relationship with the patients, not just a relationship when the patients come to the surgery to see the doctor." (North East, practice manager)

"Actually how they've just become part of the practice, they're not an add-on, they're not different, they just come along, they have a cup of tea, we decide we're going to do things and we do them together." (North East, practice manager)

"We've got a few champions at (practice) who are absolutely brilliant, one of them, it's like she works there, she's got the code to the door and she goes in, has a shelf with her stuff on and she does signposting." (East Riding, project worker)

GPs' EXPERIENCE OF THE HEALTH CHAMPION WORK

All of the GPs were very supportive of the health champion work but due to their increasing workload they had little contact with the health champions and most were unsure of the health champion activities.

"Because this practice has struggled, unfortunately with GP recruitment and the GP's ability to draw themselves away, I think in that area, I don't know whether the GPs have felt any benefit because they've not been able to lift their head up and look above the parapet." (Sheffield, practice manager)

One GP who had gone out with the Walking Group a couple of times and attended a Community of Practice Meeting, still was unsure about the health champion activity.

"The things I'm aware of are the walking group, the coffee afternoon, there's a language group for people to come to and I know they sometimes do meet and greet with people, so they're seeing people, talking to people and helping them negotiate their way around the practice. That's all I know about." (Bradford, GP)

One GP was fully informed due to the very proactive practice manager.

"We've got a reading group, we've got a men's group, a knit and natter group, we've had a few, they've been brilliant, the patient champions organised a Christmas dinner and we've recently had a tea dance as well." (North East, GP)

GPs signposting patients to health champion activities

GPs said they did suggest to patients that they might like to consider joining a health champion group but most of the time they didn't know if the patient had acted on this.

"I'm not aware of any specific cases where I've made a suggestion and they've turned up but then I wouldn't necessarily be aware of that because I'm not there just to see who is at the group. I've mentioned it to quite a few people who have thought it's a good idea but I suspect from the numbers that Aileen's describing and the fact that most of them are regulars, they haven't taken us on up on the offer of doing that." (North East, GP)

"I think it's been beneficial for the people who've participated, I have recommended some people sort of specifically one to one to take part because I think it would be really valuable for them to feel valued, but none of them have really taken up that opportunity." (specialist service, Consultant)

There was some evidence from health champions that GPs had suggested the health champion activities to patients.

"Here was a lady that came to the first team craft group, a patient from here and she was a lovely lady, she'd lost her husband six months previously, because of that she was depressed and the GP told her to come along, she was going to the GP all the time." (Bradford, focus group)

"I formed a group up with another lady and we're aiming to provide stress relief and relaxation for people and it's going really well and this week, I heard that we'd had a referral from one of our doctors." (Calderdale, health champion)

One GP described how helpful it was to be able to refer patients to the Christmas Dinner provided by the health champions.

"The Christmas dinner was excellent because as a doctor, I could identify people that were going to be on their own at Christmas and often there is nothing that you have to give them but to say, "We're organising a Christmas dinner, if you want I can give you details about it", was very helpful." (North East, GP)

Noticing a difference

Some GPs had noticed an improvement in the well-being of their patients (see also 'Patients Benefit', P.12)

"I think there have definitely been, I can think of one person in particular where there's definitely been benefits in socialising and a person that was new to the area and this was a way of them making friends and meeting up with people and getting involved." (North East, GP)

GP involvement in meetings

GPs are not generally involved in health champion meetings but as one project lead pointed out this was not due to lack of support for the work.

"I've never really got a sense from the GPs that they didn't get it or didn't see the point. They're all for it as long as it doesn't take up any of their time." (Bradford, project lead)

Occasionally, a GP did call in at meetings.

"I have. I've bobbed in and out when I've stayed late sometimes, I was at the AGM and what else have I done? They had a meeting which I bobbed into when they were talking about cancer and bowel screening and that was really interesting because we're trying to increase the rates of uptake for all sorts of screening." (Sheffield, GP)

In the case of one practice the practice manager ensured there was GP involvement in health champion meetings.

"I think it's down to our practice manager! S involved, well I was the named GP to get involved with it so I had a named GP and we fed back to the practice meeting and right from the start, the doctors were involved and she made sure the doctors were involved and made sure we knew what was going on." (North East, GP)

The potential for changing the ethos of the practice

One GP who had joined the Walking Group on a couple of occasions and attended a Community of Practice meeting noted the difference in her relationship with the champions and the change in ethos at the first health champion meeting.

"People are more straightforward about what they discuss with you, what they want to offer, what they want to share. There's less of a negotiation, it's more equal." (Bradford GP)

"I have talked to a GP colleague actually, thinking about it, I would say that the initial meeting, when the health champions, the potential health champions came and met all our team during our protected learning time, was very interesting and enlightening for all of us and partly because we were sitting in the waiting area, the hierarchy was challenged and we had to relate to people in a different way....For me, that was a very important stage because that increased people's confidence but it also challenged receptionists and doctors who were used to relating to patients as out there and separate." (Bradford, GP)

What would GPs say to other GPs about the health champion work?

GPs described the health champion work in terms of patient self-care but they reported that many of their colleagues were sceptical. One said he thought his would need statistics to prove that it was working.

"I would say to them, "You know all the things that come up in consultation which feel as though we're telling people what to do or we're advising them all the time, this is a way in which we can negotiate a different agenda around health and health promotion", so I would say "We can help people be less dependent on primary care and general practice, by enabling them to do things voluntarily for themselves and other people in their community". I buy into that but there are plenty of people who don't see what I mean." (Bradford, GP)

"I think everyone will go that's great but what proportion of people are we seeing out of the 14,000 patients we have here or the number of patients that turn up every day on a regular basis, what proportion are going through this process? That would be nice to know." (Bradford, GP)

One GP was able to tell colleagues the difference the health champion work was making to her surgery.

"I told them how successful it is, with the patients that were coming frequently that are now supporting themselves more. It's a bit like a social prescription really, they've got a support group there, they've got interests, so I always say it's worth doing, it's worth organising, it takes somebody in the practice to really be enthusiastic and we're lucky we've got (practice manager) and all the other GPs are really positive about it as well." (North East, GP)

RECEPTIONISTS' EXPERIENCE OF THE HEALTH CHAMPION WORK

What do receptionists know about the health champion work?

Many receptionists did not know a great deal about the health champion work.

"I think they're trying to do a good thing, I don't know too much about them, I think if they can get the patients and everything involved in what they want to do, I think it is a good thing and they're taking their own time out of their lives to help people." (Bradford, receptionist 1)

"Yes, they come into the surgery and they've been asking questions and also they've helped us out with flu clinics but mainly, everything else is a bit of a blur because we haven't really had a lot of dealings with it." (East Riding, receptionist)

Most of the receptionists did not know the health champions by name or only knew one or two of them because they were regular patients at the practice.

"But I think when they've come in, from a reception point of view, we're that busy, they've come and we've handed them the tablet (Friends and Family survey) and they've got straight on and speaking to the patients, obviously we have a talk but we probably wouldn't know the names on the basis, or just saying, because the girls are part time, everybody is in and out on shifts so it's not somebody regular that's here all the time to get to know the names." (East Riding, reception manager)

Receptionists undertake health champion training

There were some practices where receptionists had been on the health champion training course and understood the work but this was the exception. One practice manager recognised that the receptionist was the most appropriate practice member to interact with the health champions and the patients because they were on the frontline of the practice.

"Yes, A, one of our receptionists, we sent her because we know that the practice champions' training was for patients but I felt very strongly that for the practice to engage effectively, some of the practice staff needed to do the training as well. I'd been along and seen and heard a little bit of it but I hadn't done the training but the receptionist that we feel should lead on the practice work went and did the training and now she's coming back and saying, "Such and such should do it", so we've got another receptionist now going to the next one." (North East, Practice manager)

Receptionists taking part in health champion activities

In some practices the receptionists were taking part in health champion activities. At one practice (North East) a receptionist initiated and ran the book club. At another (North East) the practice manager encouraged receptionists to join the walking group and Singing Group when workloads allowed. In another practice (Bradford) a receptionist ran a relaxation group.

"So she said it was really nice, having that opportunity to learn about how it's been for her and coming into the area and she said, "I can now relate to her better at the front desk" and I thought if you wanted to encapsulate anything, there it is, in that one interaction." (North East, practice manager)

"Yes, I go because I helped Mary to get it going. I've got like two people who go, usually from another singing group, from the carers centre and they live just off Wellbeck Road which is in this area, I got them to come." (North East, receptionist)

Receptionist ideas

As receptionists have a good knowledge of the patient population they had ideas on how the health champion work could progress. In one practice, the receptionists had difficulties with patients who did not speak English so they asked the health champions to start a Conversation Club.

"Like the conversation club has been one they've really pushed for and really encouraged patients to attend, when patients have been coming and having that language, communication for booking an appointment, they've said "Why don't you come along to conversation club on a Friday morning?" and they've been really helpful in signposting people and getting people to attend that." (Sheffield, project workers)

"...and so getting (receptionist) involved in this has really helped - the way I describe her as she's gone from being Eeyore to being Tigger. "I've had this idea and that idea"." (North East, practice manager)

There were also ideas on how the health champions could feedback on their activities to the practice. (See 'Feedback Mechanisms', P.43)

"We have a reception meeting every month so if they wanted us to give an update on other activities that they're thinking of doing or if we've got any suggestions, then I'm quite sure that (reception manager) would allow them to come to the reception meeting." (Bradford, receptionist 4)

Changing the role of the receptionist

Where receptionists knew about the health champion activities they were able to suggest groups to patients. Their knowledge of individual patients allowed them to identify people with non-clinical needs, such as social isolation, that could be helped by taking part in the health champion activities.

"Definitely on reception because I know that some patients come when they're really stressed and they need help about certain things, we can like, I feel better being able to give them a leaflet about help and stuff, so it's easier, it does make it easier because you feel like you've helped them, in a way." (Calderdale, receptionist 3)

"In fact we referred a lady that's on her own, that's very lonely, she came into the practice about 8/9 weeks ago, stood at the front desk talking to my receptionist and she was so low and so upset and she just said, "I just feel so lonely", so we referred her onto Sheffield Wellbeing and the practice champions." (Sheffield, reception manager)

"Whenever I'm talking to people I'm saying "Look, why don't you join?", if I speak to someone on the phone, I've been here over 20 years, they say "I'm a bit fed up", I say "Why don't you come to the champions?", or "why don't you do this or that?" (North East, receptionist)

One project team had developed their strategy and were aiming to have the receptionist as the main contact for the health champions because of the difficulty of getting hold of Practice Managers.

"The reception staff know patients a lot better than the practice manager, they may live local anyway but they see them every day and it's a lot easier for a champion to walk into a practice and say, "I need all these leaflets distributing in the practice", and giving it to the receptionist rather than the practice manager to sort out." (East Riding, project worker)

Receptionist involvement in health champion meetings

In some practices receptionists were involved in health champion meetings.

"She asked if one of us would like to volunteer to go along to the meetings with her and I kind of volunteered myself. ... it's so they've got somebody else as a figure as well within the practice, that they know they can talk to." (Reception manager, East Riding)

"We always ensure that we make time, everybody's busy and we could all quite easily say we just haven't got time to go and sit in that room for half an hour and talk to them. But we feel it's a link that we need here at the practice, so we make time to go and sit with them and talk to them about it." (Sheffield, reception manager)

HEALTH CHAMPION ACTIVITIES

There are many different health champion activities from Walking groups and Knit and Natter groups through to Kite Flying and a Tea Dance (Full list available with this report)

There were many examples of health champion groups and activities that were thriving but there were also many groups that struggled to get off the ground. However, the health champions often re planned their activities sometimes by altering the time and day of the group, or altering the venue, or joining one group with another. The groups were always evolving and adapting and these changes could take place quite rapidly.

Health champion activities working well

There were many examples of health champion activities that were going well. At one practice the receptionist had asked the health champions to set up a Conversation Club for patients who didn't speak English, which was very successful and helpful to the receptionists. At another practice, health champions had provided a Christmas Dinner for those who were on their own on Christmas Day.

"I think there was probably about 30 odd people on a full day, obviously numbers might dwindle because that's like anything that you set up, you have to constantly drive it forward." (Sheffield, practice manager)

"We have a chap comes that does a sing along and he does all the old music and we have a raffle and a bingo and a buffet and it goes really well. I did one on Monday and I got 43 people." (Sheffield, focus group)

"It (Pain Support Group) varies from week to week, I think we've got about 50 people on the books, sometimes we can have ... we've had 20, maybe more and the last week, nobody came but we think that was because of school holidays and the other thing is, pain is just one of the symptoms of other conditions so it's how they are on the day." (Sheffield, health champion)

"The flu fair, the practice staff did the flu/clinical bit but the practice champions organised the self-care elements of the flu fair, so we hired the local church hall, they had the Fire Brigade there, Arthritis Care, a whole load of other organisations that would then support patients and the patients had the most wonderful time." (North East, practice manager)

"On Christmas Day, we held a Christmas dinner for isolated patients and we had a refugee family who used to use casualty as their default for care provision, they came along and had Christmas dinner and had a lovely time. Another lady came along who isn't a patient in the practice but who was referred to us by Age UK, when I went to visit that lady, she said to me, "I just want to get out of the house for one hour a

week" and she's now out doing four different events every week." (North East, practice manager)

Checking what's already available in the community

It's important to check what groups are already operating in the local community before creating a health champion activity. Some groups have failed because there were already similar groups in the local communities.

"What we tend to do is look out there and see what's going on because there's no point in duplicating things if there's no demand there. Sometimes, I feel that we're at the tail end of it, there's already something in place via the NHS or whatever, that there's no need to, we can just direct people to wherever because a lot of the villages have cancer support groups for its people, so it's finding a slot in there, getting something started that's popular." (Bradford, focus group)

"I was advised by (practice manager) to go to the health visitors clinic...there were about 30 mums in there with their babies up to eight weeks old and they all go on a Wednesday to a mums and babies group, so she told me that she didn't think there was any call for it and there's various other groups in (town) particularly, and I think there's a couple in (town) where I live." (East Riding, focus group)

Starting and building up groups

The process of starting a group and building up the numbers of people attending can be challenging. Sometimes building up numbers is just a matter of time.

"Since before Christmas, about October I think we started and we got nobody the first week and then the second week, things were catching on I think somehow, I don't know how but then we got two or three and it's got to about eight attending now, jump on and off but they're coming..... I'm wondering about extending it because people don't want to go home sometimes, we do 10.30 to 11.30 and I'm thinking of extending it to 12 because people just don't want to go." (Calderdale, health champion)

At some practices champions have been asking what sort of activities people want to help get groups and activities going.

"Every event that we've had and all the work we've done on our consultation with patients, one of the questions that we've asked is, "What more can we do for you?", so they said they want a fishing group and a men's group and a this group and a that group but consistently a key message has been that they would like a tea dance." (North East, practice manager)

"(Women only Support Group) I think everyone, to start off with you do have little struggles and things like that, I think once you start running and the women who are there, you ask them what they want, then you can ... you're making that difference. We want those women to get involved, tell us what they want out of it, I think that's why it's working, so you're working with them." (Sheffield, focus group)

There were often challenges when health champions became unavailable due to sickness or a change in circumstances, or long term holidays.

"There was an initial communications group, of which I was one and two other ladies that were in that... they're no longer involved, A had other things because she had other things she had to do and J because her husband got a job in (town) so they moved down there just before Christmas. But that's gone by the by." (Bradford, focus group)

"A couple of the champions who ran it (Walking Group) were ill so they pulled out, they've not come back yet, they're still involved, they're still in touch, they still get the emails and they still speak to R but due to ill health, they said they just can't do it." (East Riding, project worker)

Groups evolving

Groups were continually evolving to adapt to take into account what the health champions were learning about their groups.

"It's an all women group. We did speak to a lady the other week that one of the other ladies had brought and she said "My husband would love to come" and we were saying is there an outlet out there that we need to do for men." (Sheffield, health champion)

"To be honest, the social things at the moment haven't been particularly successful, which is from that I came up with the idea of maybe something like a buddy scheme would be better first, where they'll be a champion or two champions in clinic and clinicians would come out and say, "These people are here, if you'd like to have a chat with them", because we've been where they are now and I know when I was really ill, which I was at one point, that would have meant so much, just to talk to somebody who has been there and to say, "Things are a bit crap now but look, you can move forward" and then from that, they may come to the social things, they may want to become a champion themselves." (specialist service, health champion)

"We are trying to introduce other things into the pain support group like a healthy eating plan but that's something that we're going to have to go away and see what we can learn, what the nutritious foods we can bring into it." (Sheffield, health champion)

"The room is totally wrong, it's very impersonal. We've got four people there, three of which were from this surgery and one lady from another surgery. So we've now

moved it to the (venue) opposite the Police Station, and that's a much better room." (Calderdale, focus group)

Links with the community

Health champion groups and activities naturally extended together to groups in the community in a variety of ways.

At one practice, the Singing for Health group combined with the local dementia choir.

"The lady from the Alzheimer's Society, she came to our group at St Andrews, she then invited us to go to the Baptist Church and that's how it all developed and of course the more people you have, the better sound you make." (Bradford, focus group)

A health champion who had undertaken additional training to enable him to teach chair exercises was asked to take a group in a local care home.

"Well S is in an elderly peoples' residence, and I've got family in there. In the group we were talking about how can we encourage the community, and I mentioned it and they were like, "yes what can you do for us?" Because the activities manager there hasn't had some of the training such as M's had for Move It." (Calderdale, focus group)

Searching for a venue to hold a choir resulted in local monks becoming involved in the singing group.

"They've got brothers down here who live in the vicarage and I contacted them first and they were very supportive but Brother D, who's in charge, has been very ill and he's convalescing at the moment. We don't see so much of the others but Brother M does come." (North East, health champion)

Some Practice Managers are happy for other members of the local community, not just patients, to join the health champion groups.

"Anybody, it doesn't have to be practice patients, any of these initiatives if you like are open to anyone who lives in the area, we didn't just say for patients only, it didn't matter, bring your neighbour, it doesn't matter if they're a patient or not." (North East, practice manager)

Health champions linking across practices

Some health champion groups were beginning to join together for some activities. Two practices with a Walking Group joined up to form a joint Walking Group.

Health champions from different practices met each other at Community of Practice meetings and subsequently some started to meet up locally to exchange ideas and support each other. In one project area the champions met informally in a local pub once a month.

"Yeah when we have the meetings for all of Calderdale yeah, they ask us what's going on. So I'll be going next Tuesday to their diabetic support group." (Calderdale, focus group)

One practice manager felt joining with other champions would help with more adventurous health champion activities.

"When our champions said "We're going to do a health fair", I thought a shed load of work for me because I could just imagine this tiny group of health champions and a health fair is a really ambitious thing to aim for, who's going to be the one to sew it all together, that's going to be me. But in fact, if they want to borrow people from the other groups to make it happen then you know, we could possibly share the load!" (North East practice manager)

"So there's something, that kind of next step, about growth and what that generates then across the whole community, if you've got things happening like that kind of linking together, and I think that's quite interesting to observe and see how that develops." (Bradford, Project Lead)

Ideas the practices weren't happy with

Practices have to be comfortable with the activities that champions want to set up. One practice was unhappy with the aims of some champions.

"An idea we had was to do a cycling event around the Tour De France, we had seven months' notice, so we said "let's do one the week before, we'll do it for charity, test the route, where we want to do" but they wanted to get wardens and high vis jackets and it just, they totally scaled it out of anything that was possible for the volunteers." (Calderdale, practice manager)

"I was talking about going to Morrison's, Tesco and whatever and saying any food you're throwing away, can we have first dibs at it because there are some old people that could use it, "Not doing anything like that"." (Bradford, focus group)

Health champion activities not taking off

Understandably, health champions were disappointed and demoralised when the groups they had put so much effort into didn't take off.

"A bit disillusioned now, we started up baking buddies...we've had three meetings and nobody's come, we've put leaflets out, it's been in the press but we've had no

takers. You just, I don't know ... feel you're wasting your time don't you?" (East Riding, focus group)

Activities helping the practices

Health champion activities were often focused on helping the practice. The most common activities were helping out with the flu clinics, carrying out the Friends and Family survey and signposting patients to local services. In the flu clinics health champions were greeting patients, giving out information and helping them with coats. It helped the flu clinics run more smoothly.

"One of the areas that the patient champions have been helpful in, the signposting group, they've been involved in helping looking at things like the friends and family survey and they were involved with the flu campaigns as well and that's been helpful. From that, some of the patient champions have shown an interest in the patient participation group, so that's been good." (East Riding, GP)

"We helped out with the flu jab, we came in and chatted with the patients, helped to take their coats off and things like that and stated what we were trying to do and making people more community minded because this is what we wanted to do, a lot of people just need to have a chat." (North East health champion)

"It's a good way to communicate with the patients by getting them to fill (Friends and Family) in, that's just to show the GP what these patients are lacking anyway and what their needs are but it's also a chance for us to speak about that point, about what we offer. Like I said, raising awareness or sharing the activities that are available locally, like what kind of health courses are there, people with weight problems, things like that." (Sheffield, focus group)

There were, however, instances where practice felt let down by health champions.

"Two said that they were going to do that and then they didn't turn up. You get ones that are really good, reliable and then you get ones that say they're going to do stuff and don't, so that tarnishes the credibility in terms of commitment." (Bradford, practice manager)

"So we asked if Practice Health Champions would come and help us with that and I think they were absolutely stunned at, you know, it wasn't a nice little skate in the park and we didn't get many back after that." (Bradford, Practice manager)

Helping in the practice has been recognised by project teams as one way of getting health champions activities going quickly, helping practice staff and health champions to get to know each other and increasing the visibility of the champions in the practice.

"So again we had to put a bit of pressure on the practice and say, we need them to do something, we need some initiatives what you want them to do and even then, it wasn't coming back so what we did was we looked at the national initiatives for health like in February, there was the healthy heart initiative, in March I think it's smoking, so we got onto the champions and said, "We want you to sort out ..." because we've got some good champions there and they're prepared to get involved." (East Riding, project worker)

ORGANISATIONAL AND COMMUNICATION ISSUES

There were difficulties in organisation and communication as one might expect in a new venture which is very different for both the NHS and often the champions. As one health champion said "communication is a great thing isn't it and a difficult thing."

Finding a suitable way to communicate with champions was sometimes a challenge.

"I think there is an issue with people that aren't on email, there's three and you're one of them, a couple of other people have got email but for some reason it's not going through and was blocked. I take your point, I think we need to find another way of notifying people that aren't on email." (Bradford, focus group)

"In my class just there now, one of the girls has just taken everybody's name down because a lot of the people there were saying, "We didn't know what was happening", so I don't know whether or not communication is getting out to everybody." (specialist service, health professionals)

There were instances of practices saying rooms were available and then health champions finding that they weren't.

"Last Friday morning, no-one could get in the room because (practice manager) was in here having a meeting and wasn't told that we were having one. So that's a breakdown in communication." (Calderdale, focus group)

In one practice the health champions were offered the regular use of a room for a coffee morning but the practice didn't tell them when it wasn't going to be available. It was demotivating for the champions.

"So out of six weeks we've been doing it, about two of them, we didn't get, nobody rung us to let us know, which is annoying. And I were thinking I might as well pack it in, you know?" (Bradford, focus group)

The staff had also given the wrong time of the coffee morning to an elderly gentleman who was very disappointed, especially as he did not live near the surgery.

In another practice the practice manager had said he would send a text to patients about the Diabetes Group but there was confusion over whose responsibility it was to initiate this. Consequently the text didn't go out and no people attended the group.

Some practices commented that champions sometimes didn't take action to organise activities or just didn't turn up.

"We had an idea that they could do a Christmas Carol concert for us, get organised, get a school to come and sing and do something Christmassy or get a Father

Christmas, it didn't happen, there just seemed to be a lack of organisation maybe within themselves." (Calderdale, GP)

"(Project worker) had emailed and said he was going to get some of the champions to come in and hand out the posters and talk to people and that didn't actually happen....I kept emailing saying "No-one's come in yet to collect the posters, nobody's been in the waiting room to dish them out"... so to be honest at the beginning of the week, I was getting a bit anxious because I knew it was Thursday so I ended up putting more flyers out in the reception area." (East Riding, reception manager)

There are many health champions who don't respond to emails or other contact which makes it difficult for project teams, the practice and other health champions to plan activities. One health professional suggested that the lack of communication maybe due to lack of experience.

"I don't know, you just don't hear back from them. You send out an email, mostly to those who have responded before, the same old, same old, you send them an email, then you hear back from half of them." (East Riding, health champion)

"We've got maybe three or four that we really struggle to get hold of and no matter how many letters, phone calls we've done, emails, no response to and then you have others who are really good at communicating, as well as being here every week at that session, that helps as well." (East Riding project worker)

"I think for a lot of the patients, they've missed out on work/life experience, home/life experience, they're not used to this level of communication whereas we are and it's that passing on of skills." (specialist service, health professionals)

FEEDBACK MECHANISMS

There were few instances of regular communication between the health champions and practice. This meant that often GPs did not have clear details of what the health champions were offering. Some practices did have mechanisms for communication with health champions. At one practice this was achieved by an overlap of membership between health champions and the PPG. There is always a GP in attendance at the PPG meeting.

"D, who is one of the champions, is also one of our patient reference group members so when we have our patient reference group, he often brings in his leaflets and gives us an update as to how things are going." (Calderdale, Operation Manager)

One practice manager, who was very involved with the health champion work, fed back information on health champion activities to GPs.

"They have regular meetings now with S and basically then she can feedback to us what's happening, she's in regular contact with them." (North East, GP)

In one practice where there very few health champions the practice manager has personal contact with each one.

"Because we're so small, it's very easy to do, I can ring them up and say, "We haven't seen each other for a few weeks". On Saturday morning, if I've been in, because we've been having work done recently, one of our champions also likes to do the posters in the waiting room and help with the displays, so on a Saturday if I know she's up early, I pick her up on the way and so it's just whatever." (North East, practice manager and GP)

Feedback on health champion activities could also be achieved through the attendance of the practice manager at the health champion support meeting but this didn't always happen.

"The most proactive one by far has been E. ... He's the only practice manager that comes to the support meetings." (Calderdale, project lead)

In a large practice with project workers on site (Sheffield) daily information on the health champion activities were put into pigeon holes and on desks first thing in the morning. They also put a monthly update in the kitchen that the GPs used.

Suggestions on how feedback can be improved

When staff were asked to consider ways in which feedback between the champions and the practice could be achieved or improved there were many different answers; all of them adapted to fit with the existing practice routines.

One GP suggested that the updated information on the health champion activities could be sent round to staff in their regular 'FYI' email or through the waiting room electronic screen. He felt that practice meetings have a heavy agenda and so it wouldn't be fair to ask a health champion to attend in case they couldn't give attention to the item.

"So a list of activities of what's going on is fine, the big issue is how many lists are we going to have? And how often is it updated and all that sort of thing? ... Unfortunately the only way of knowing what's going on, ... is every now and again getting a bit of an update about what groups are happening, which I think is a difficult one because we have lots of lists that come through and you get list overload... The way we communicate ... is an FYI that we have every week as an email and the difficulty about (practice) meetings is they're just packed and the worry about a 10 minute slot on a regular basis is that it gets squashed." (Bradford, GP)

Another GP, who had gone out on one of the walks with champions and had attended a Community of Practice meeting, also felt as though she didn't know enough about what was happening with the health champions. She suggested that there could be a lead champion who could be in email contact with her or liaise with one of the receptionists.

"I feel as though I've put time in and gone to the meetings and I went on the walk a couple of times and things like that but I don't feel as though I've got enough contact with it... maybe more emails directed at me, I don't want to say it's about time or money, it isn't, it's about communication with me and me understanding it. So it might be that if there were one particular health champion that I knew I was just liaising with, then I would do it like that really and send her or him an email and say "Just give me an update once a month of what's going on and who's involved" and I could be the link back or one of my receptionists could be." (Bradford, GP)

A receptionist suggested that champions could come to the monthly clinical governance meeting so that staff could get to know them and what they are doing. She was also interested to find out whether the patients she had recommended to the groups had actually attended. Another receptionist felt that photos of the champions and circulating the minutes of the support meetings would improve communications between champions and practice staff, including GPs.

"We have a clinical governance every month and I know they've been to that once and that's when we met them properly, so I think if they come to that, there'd be a 10 minute slot because it's all day...so if they came to that, I think that would help... so we could get to know them better and what they do and how they're getting on and stuff because we don't really know what's happening, we don't know if people are coming to these support groups, we're sending people off to these but we don't know if people are actually going and I'd like to know that, how they're getting on." (Calderdale, receptionist)

"We could have a picture with the people that were on it and that we did get minutes and I circulated that around everyone, show employees what the patient champions have done and achieved." (East Riding, reception manager) In the case of the specialist service clinic, which only takes place one morning a week, a health professional suggested they could have time at the end of the clinic for updates between health professionals and health champions.

"At the end of a Monday clinic would be ideal, when everyone's here. Could just have like 20 minutes at the end or something." (specialist service, health professional)

The professionals also felt that the champions could advertise their Facebook page and their activities on the screen in the clinic. Then they could signpost patients to health champion activities.

Waiting to be directed

Many champions felt they were waiting to hear from the practice what they wanted the health champions to do in the practice

"No, I think I've said, I think it's got a future but I think we could have some feedback from the hierarchy, I really do and you know, like they say give us a clue what we can do. I really think that will work." (East Riding, health champion)

Communicating appreciation

Often health champions did not feel their work was appreciated by the practice even when the practice staff were grateful for their input.

"Yeah, we fed back at the last progress meeting and we have a PPG as well, so the PPG, we feed into that what the champions are doing and keep them updated as well and a couple of them have been in and had the survey done and they said what a fantastic job the champions were doing." (East Riding, practice manager)

CHALLENGES IN THE HEALTH CHAMPION WORK

Expectations

For some health champions the health champion work wasn't what they expected, or they were confused about what they were supposed to be doing.

"I used to do Riding for the Disabled, which I found extremely good for those who needed it, really satisfactory and I think I thought that the Practice Health Champions would be a bit more like that, that you're actually doing something with people and helping them to get a lot of enjoyment out of it." (Bradford, focus group)

"So funding is a specific skill, so you could have a practice volunteer funder, you could have a practice volunteer greeter, it's defining the roles and then when people come, they can then say to them, "We have these roles, we have people that are back room that do funding and admin and keep the diary, or we have people that are the champions facing the surgery and they help on this and do that, what sort of role would you be interested in doing?"." (Calderdale, focus group)

"What would be a good idea is for the practice champions to observe the Pudsey one working, that would maybe give them an idea of what to expect. That would have been good." (Calderdale, focus group)

"It might take you six months to get it off the ground because you get a group of people who are very enthusiastic and go in and then you're completely knocked when it doesn't take off. Whereas if somebody had said, "Look, keep it going for the six months", our experience is we've done things like this before, we're the ones that are setting things up, it will take you time and then you would have accepted it, it maybe a little bit more." (East Riding, focus group)

"It was all very fluffy, for want of a better word." (Calderdale, focus group)

At the specialist service there was some dispute about whether the health champions were going to operate as primarily a support group or group creating health champion activities.

"But that group's a support group, now I think that's really what I am looking for, I personally don't know how I can give support when I don't feel supported myself." (specialist service, focus group)

Ideas not taken up

Some champions were disappointed that they couldn't follow up the ideas they were passionate about.

"We were originally wanting to go into people's houses and make them a cup of tea, that's what we were originally doing, we haven't done that! Because they say you have to have lifting training and if they fall, all that experience, I said "I don't mind doing it" but nothing come of that." (Bradford, focus group)

"I'm an advanced driving instructor, I'm quite happy to give people confidence to do these things and so that they don't stuck at home and not able to get out. There's all sorts of things you can do to modify cars and everything, to make sure these people can get out ... I'm so disappointed with what I've achieved, to turn up to a practice and just fill in a flippin' thing like that (Friends and Family survey) I'm very disappointed. I'm doing it because it's important but I don't feel I'm doing any good." (East Riding, focus group)

"I think there were some quite wild ideas as well, about taking people's children off and looking after them and things. Yeah, we had to say we don't think that's (appropriate)." (Calderdale, operations manager)

Slow to get things going

One of the main challenges of the health champion work has been the slow start to projects. This seems to have been due to a combination of health champions and practice not fully understanding the work, project teams focusing on recruiting and training health champions, and DBS checks.

"But I think we are getting there now, I think initially, that's absolutely right and I got to the stage where I thought "I'm not going to bother with this anymore because it's a waste of time", but it is now growing. How long has it been going for? Just over a year?" (Bradford, focus group)

"And he says, "waste of bloody time, I've been here about six weeks now and we haven't done anything", he says "I'm giving it up as a bad job", he said "I'll come for next one and if it's still the same, I'm not coming anymore" and he never come anymore." (Bradford, focus group)

"They were all here and they were all giving their suggestions and stuff and they led us to believe that they were really into the idea and very encouraging it was, they agreed with it all and they were quite looking forward to it and then we never heard another bean off them." (Calderdale, health champion)

"It seemed to be a long slow process. I mean we knew at the start we were making it up as we went along. But now it seems to have a bit more encouragement." (Calderdale, focus group)

"It took a while didn't it, to get the full understanding of it and get the ball rolling, there were a lot of meetings about meetings in the beginning, there was a lot of talk

about what we might do, what we'll do next time, to begin with." (Calderdale, operations manager)

"But I think all of it's just taken too long in the beginning and I think that's why the training took such a long time and the actual doing took such a long time, there must be some happy medium and the doing and the training, once you've had your training, the doing could be a lot quicker." (East Riding, practice manager)

Health champion activities not taking off

There were many places where health champion activities did not take off. Health champions felt that it was often due to GPs not recommending their groups and the activities not being advertised sufficiently. In one practice all three of their groups were not successful at the time of the interview and nobody was sure why. It was an area where there were already a lot of community groups and they were resentful towards the GPs for not sending patients to the groups.

"I don't mind doing that, if they said to me, "Will you come to the surgery once a fortnight?", once a month for an hour and do something, then I would feel like I was doing something whereas with this project I take part in [Little Steps], I don't feel that I've been any help at all, going around places to try and draw people, the young mums in but there are just not the young mums in this area, if we went to work in the city, then I think it may be different." (East Riding, focus group)

Lack of support from the practice

Many of the health champions felt that there was a lack of support from the practice for the work they were trying to do. This was confusing where staff had seemed enthusiastic at the training. In one practice the operational manager suspected that the health champions might feel unsupported but, in reality, the staff were trying to understand the work and wondering what their role was.

"They were all here and they were all giving their suggestions and stuff and they led us to believe that they were really into the idea and very encouraging it was, they agreed with it all and they were quite looking forward to it and then we never heard another bean off them." (Calderdale, health champion)

"The backing we're getting from the doctors' practice on the things we could do is nil, absolutely nil and apart from helping them with this survey and the flu clinic, we don't do anything." (East Riding, focus group)

"I would have liked more enthusiasm from the surgery. I was expecting more. But having worked for a large organisation like social services, obviously you haven't got the freedom, you've got health and safety issues which are a big one. Like I wanted

to make drinks for people when we were talking to them, well obviously you can't have drinks in reception, and I understand that." (Calderdale, focus group)

Some champions felt they didn't have the skills to set up a group without support.

"I think it's a huge thing to then turn it back on us and say, "Right, you've got your ideas", say like we've got our baking buddy ideas, "Now it's up to you, get on with it and advertise it and organise it and get it off the ground"." (East Riding, focus group)

"In certain, yes, it has, in some ways I'm a bit worried about this men's group because it was my idea in the first place and then they thought "that's your baby, sort it" sort of thing ... I'd be very concerned it was just left to me on my own." (North East, health champion)

Relationships with the health champion group

Friendships and socialising are an important part of the experience of being a health champion (see Health Champion Benefits) but there are also some challenges around the relationships within the health champion groups. Sometimes, health champions have left due to a difficult personality. The project leads recognise that this is sometimes a problem and they have tried to deal with the situations the best way they can.

"It was also a coffee morning that was arranged for the Practice Health Champions, just an informal get together, not a meeting, at the coffee house on the corner which was very well attended and then other people arrived and it was like "you're in charge of doing coffee now and you're in charge of this" and the people that had been doing it are sitting there thinking "What's going on?"... gradually they just disappeared off the scene, the original, very keen members." (Bradford, focus group)

"It was going haywire and this particular person was just saying irrelevant things, so I said "Look, come on now, we've got to discuss this, let's get on with this"..., He doesn't say a lot except when he shouldn't sometimes ... and I kind of, when he's doing this, I say "Just a minute please, so and so's speaking" or quell him in another way, in a sense, gently but firmly." (Calderdale, health champion)

Hibernation and Drop Out

There was a high drop-out rate of health champions after the training. It wasn't always clear why people left but people suggested that some people left because the health champion work wasn't what they were expecting, or because the work was slow to start and they lost enthusiasm.

"One gentleman thought that the job was wallpapering and gardening for people." (Calderdale, focus group)

"We had one gentleman came on the training and he lasted about an hour, half an hour and decided this is not what he wanted to do. ...It was too much talking, he decided and wanted to get out and do stuff." (Sheffield, project worker)

"I think they wanted it to be more prescribed didn't they?" (North East, focus group)

"They were hoping to get, do voluntary work and then end up getting a job out of it and once they found out, they didn't come no more!" (Bradford, focus group)

"But we did have quite a core group, but there were some who, there was quite a few in Skipton who wanted to do one to one stuff; that their real passion was around isolation and befriending, which is something the practice is really passionate about, but early days we just weren't set up to do, and so some of them left because it wasn't quite what they wanted either." (Bradford, project lead)

There were some who left because they got jobs or their circumstances changed.

"But we have lost quite a few of our, particularly younger ones to working employment and things like that.... although they've got jobs, still kind of want to be involved on the periphery." (Bradford, project lead)

"People have been in for operations. That might take them two or three months by the time they've had their operation and been well enough to come back, looking after grandchildren, school holidays come into that." (Calderdale project lead)

Practices lost health champions because they sometimes didn't feel welcome by the practice and the lack of activity after training.

"Well we lost some fairly early on for just not feeling welcomed by the practices and stuff." (Bradford project lead)

"But the other thing is having known that people have come and they've disappeared since I've been a practice champion last July onwards, is that there's a lot of enthusiasm and people's time that hasn't been utilised." (Calderdale, focus group)

Often, champions were just in 'hibernation' and returned to health champion work when their circumstances changed again.

"Specifically at (practice) where we've got a high dropout rate, but they were just beginning to come back... I think a lot of them, they don't actually leave, there's things come up in their life and then they come back, they re-engage." (Calderdale, project lead)

"So we've got three champions now, well we've got one champion who came back from being away, from being disconnected ... because the walking group started yesterday, she's come back to take part and she was at the meeting yesterday, so that's quite good." (East Riding, project worker)

"We've probably lost a few and the problem with this is that they might not be active for a couple of weeks or months and then they come back because they have good weeks, bad weeks, bad days, good days so ... we've probably got 7, maybe 8 who are core and key and a few others that come in and out." (specialist service, project lead)

Challenges for practice staff

GPs

One GP felt that there should have been more connection between her and the health champions so that she wouldn't be so reliant on the work of the project team. She felt this would help to make the work more sustainable.

"I know it needed (project team) to get stuff going because we wouldn't have done it but me working more directly with them would have been better, or my staff working more directly with them would have been better." (Bradford, GP)

"Obviously we had a lot of patient champions involved from the very beginning, which was great. I feel that perhaps some of the groups have been slower on the uptake than I'd imagined they might be." (East Riding, GP)

One GP, at a practice where there were successful groups, felt that more should have been done to promote the work to the GPs at the practice.

"I think initial publicity, when it was starting off, the doctors that were involved knew a lot more that was going on and perhaps we should have had the posters up that we got up in reception sooner, with activities that were going on and contact details or perhaps there could have been little flyers produced for the GPs about what groups are taking place that we could hand out." (North East, GP)

One GP at a practice that had recently undergone a review with the Altogether Better team felt that this should have been done earlier in the project in order to give staff time to reflect on the development of the project.

"Obviously M and S came in this week for a more formal discussion, I wondered if there'd been one of those contacts sooner than now, towards the end of the project? That it might have been useful in terms of generating a second wave of enthusiasm?" (North East GP)

Practice Managers

Practice Managers also commented on the slow development of the health champion activities. There was some confusion about what was supposed to be happening in the health champion work and their role in it. An operations manager suggested that their confusion probably gave the impression to the health champions that the practice weren't interested in what they were trying to do.

"Very slow to start with, it takes time. The one thing that we do not have is time, time to get involved and time to devote to it and I suppose initially, we were told that it wouldn't really involve us but it does." (Bradford, practice manager)

"What should have happened is for me, where it's been successful elsewhere, someone should have come in early doors, in our group with me and said, "Here's what we learned, here's all the (mess) ups we made and here's the good bits that you want to take", so saves you having to make all the (mess) ups again. We haven't done that. That probably would have said us six months of grief I would guess." (Calderdale, practice manager)

"Yeah, that's it and then of course our champions can go to other practices and "This is what we do"... I think it lacked that in the very beginning. We were all a bit, "We don't know what's supposed to be happening here" and the champions were asking us and ... we didn't know what to say and I know that first, when you attended the full day training course, me and J came in the afternoon and we sat down and we were expected to lead that and we didn't know that that's what was going to happen. So I think the patients thought that we weren't interested, I think the patients think that perhaps we're not as supportive as we could be but I think that's just a time thing, that we'll obviously have lots of other things to do, all of the time and sometimes we're not always answering questions immediately, like they expect." (Calderdale, Operations manager)

"I just think it could have been quite basic and easy to do and I wonder with future projects, instead of giving the money to (NHS trust) to set up, it would have been better to give to the practices, a pot of money to recruit, if you've got a script or handbook of how to do it, then we could have put some of that to better use." (East Riding, practice manager)

"I don't think the practices originally, we've obviously engaged quite a lot with the groups and it's taken up a lot of our time, particularly with a lot of the meetings, I don't think it was open from the beginning, how much time it would take in surgery and if that had have been spelt out originally, then you set your time aside. But it just seems to have taken a long time to do things." (East Riding, practice manager)

"I think the support should have been longer and I think we could have done with more of (project worker)." (North East, practice manager)

Receptionists

The receptionists were also confused about the nature of the health champion work and didn't really know who the health champions were.

"I think the way they explained it to us, they explained everything about them without telling us what they actually did, it took us a long, long time to get us head around what it is and I think ... I don't know, I think we don't really see much of them and it would be nice if we had like meetings with them once a month." (Calderdale, receptionist 3)

Challenges from the perspective of the project teams

The project team members, with their wide and detailed knowledge of the health champion work had several ideas about what they would do differently, and some of the changes had already been implemented.

The project teams recognised the need to explain to practices more fully their role in the health champion work and the amount of time this would take.

"I think now we know what's expected from the role and we know that volunteers are, not always, you know, sometimes they take a longer period of time to get up to a point of doing activities. I think it really is about the beginning, setting the foundations of the expectations, what you want from the practice, the expectations, that the GPs are expected to go to x amount of meetings...I know it's supposed to be about co-production and a lot of people talk about co-production but what does it actually mean?" (Calderdale, project lead)

There was a need to focus on recruiting some champions who had the skills and experience to run groups effectively and reliably. It was a surprise to some project workers how much support some health champions needed to set up a group.

"I think maybe if we did have two or three practice champions that were more able to lead. Say for example, we'd got one who'd taught English as a foreign language and was able to take a lead with the conversation group; that would be wonderful, somebody that you could rely on and you knew that they'd take that role effectively." (Sheffield, project worker)

"We've found now the volunteers we're getting through are a lot more enthusiastic, happy to do things on their own, I think because at first, we had to recruit so many in such a short time, we were just kind of taking on anyone and everyone that would do it, just to get those numbers and they perhaps weren't the best people for the role. The people that have come through now, these are the people that have sort of stayed on, they're very involved in their community, there's a lot going on and so they've got lots of connections, very involved." (Sheffield, project worker)

The delays in starting health champion groups led project teams to think of having activities ready for new champions to become involved in.

"I think it's more that the volunteers were expecting to just be able to get into something straightaway but because they needed all the handholding at first, I don't know, maybe look at making sure we already had something set up to feed some of the more, to feed people into perhaps ... when they couldn't get started straightaway." (Sheffield, project worker)

The training was controversial with many of the project teams. One of the concerns was the name 'training' and another was the length and content of the 2 day training.

"I don't think we would have put people through two-day training course, I think we would have something a bit more fun with them and almost organised a series of, let's call them induction dates, we wouldn't have called them that but we could have organised maybe 10 across the year and when we welcome people and it's that kind of language we should be using." (North East, Project Lead)

In Sheffield there were 3 layers of administration between the project lead and the health champions. The project lead felt she should have been in more direct contact with the practices and health champions. Training needed to be staggered so that project teams could more easily support health champions into the work.

"I would have tried doing it the way that it works in the other areas, having just the GP surgeries. You know the saying, too many fingers in pies, I'd liked to have been working directly with the GP surgeries a lot more... I wouldn't have had a large number because we had to do large clumps of recruitment at one time, right at the beginning, I'd try and stagger it over quarters so it's not one lump at the beginning and one half the way through; they would be divided up into quarters and you have 10 to recruit each quarter because then you can concentrate more on one small number." (Sheffield, project Lead)

"The model hasn't necessarily worked and for me, it needed to be a much more flexible model, every area's different, whether you're us in East Riding with your older population versus your inner city practice which is obviously very difficult and there's a higher rate of ethnic minority etc." (East Riding, project Lead)

One project lead recognised that for some health champions it took some time for them to build up their confidence to initiate an activity and lead a group.

"Yeah I think probably the champions, it's getting their activities set up, but I think a lot of that has been down to building confidence and I don't think you can put a time limit on when people are ready to lead an activity. It was set up that within three months they've got to have led an activity, but for some of them they were nowhere near confident enough to do that, yet they were still coming to meetings every two weeks so they were engaged." (Calderdale, project lead)

In the view of one project lead there were some health champions who did not understand the self-directed nature of the health champion work.

"There's individuals who still a year later would go, "I don't get it, I don't get what I'm meant to do, where's the job description?" and I think we've got a few champions like that at specialist service as well." (North East, project lead)

All project leads recognised that there were significant difficulties with disruptive personalities in the health champion groups. Although the training includes sessions on working together respectfully this seemed to have no impact on some individuals. Project leads were in a process of learning how to manage these situations.

"On the whole they're really good, but you do have your people issues. You always do. There have been some challenging personalities. There has been the odd conflict we've had to step in and just help resolve...I mean the training does focus on relationships and working as a group, the dynamics, roles within a group. It addresses all of that, which ultimately does give you something to go back to." (Bradford, project lead)

"In other practices, we have asked certain people to leave, we haven't done it much. One practice ... there was a champion who, she can be incredibly difficult, she's got a range of health and mental health problems, in a meeting she can go from being incredibly happy, to tearful, to quite aggressive and angry all in the space of 10 minutes, quite hard to have around if I'm honest." (North East, project lead)

"There were two friends that were really close, they had a falling out and it had an effect on the whole of the group... It brought people's moods down because they didn't want to see them arguing, ... and they were being dragged to two sides...I know the supervisor sat down all of the group and said "We're going to come up with rules, these are the rules", when you come into the group, any differences between you are left outside, it's a group, it's a community group so you lose those differences outside the front door and then pick them up on your way out." (Sheffield, project lead)

"So I've had to have two conversations with her on the phone and say to her, "Look, I need to be really clear around the discussions that you've been having and what you're saying and how that's going to impact and hurt other people" and we've had to have that really hard discussion and she's got it, but at the same time she's been quite manipulative with it and she gets other champions' backs up and we've had three, four champions leave because of her specifically." (East Riding, project lead)

One project lead focused on nurturing the bonding of groups to avoid potential difficulties.

"If the meetings happen in a pub and they're not really a meeting and a few other nice things happen, they bond quickly. So it's that kind of little thing we try and sort of do because then when people turn up to the meetings, they're more forgiving because you've had a drink with that person or you've met them for lunch ..." (North East, project lead)

SUSTAINABILITY

At the time of the interviews the health champions and practice staff were just beginning to consider the sustainability of the health champion work. Many champions had only recently realised that the funding would end soon and that they would be no support from the project team. They were shocked and disappointed and felt it would have been better to know from the beginning when the support was going to end.

The Practice Health Champions and practice staff had many ideas about how the work could be sustained and each practice approached it differently.

Funding a future

One of the practice projects (Bradford) has already been funded by the CCG to develop the health champion work in eight more practices and another project (Calderdale) has funded the Altogether Better team to support the work in a further five practices. Another was determined to keep the work going through their current NHS structure.

"We'll sustain the champions we've got and we'll come to some agreement with the practices that we've got, to ensure that the champions that are there are sustained and supported but I also think there's an element of trying to further expand the model to practices we haven't yet worked with." (East Riding, Project Lead)

This is sustainability on a grand scale. There were other ways that practices and health champions intended to make the work sustainable. One group of Practice Health Champions had already made themselves into a charity (Bradford) so they could bid for small amounts of funding from local organisations, and they were certain that they would be able to get some funding. At the same practice the practice manager didn't feel the work was sustainable without continued funding from the CCG for the Health Education Officer who had organised much of the health champion work. However, she felt it was important for the group to continue because it meant the practice could demonstrate a "good level of patient engagement." Some groups were considering making small charges (£1-2) for attendance at the group activities.

Some Practice Managers felt the work would be sustainable (Calderdale, Calderdale, North East) and some didn't (North East, Bradford, Bradford, Sheffield). Ironically, practices where the health champion work was most developed were the most vulnerable because a lot of effort had been made to get the activities off the ground. In the case of one practice (Sheffield) project funds had been used to pay for class tutors and this clearly wasn't sustainable without funding.

"I think the way to keep it sustainable in Sheffield is to get the funding from the CCGs and do it the way that we do it." (Sheffield, Project Lead)

One project lead felt the key to sustainability was preparatory work with the practices before they even recruited health champions.

"Even on reflection for sustainability purposes, I would probably definitely look to put a really clear model of planning into that structure and doing a lot of work with the GPs and the Practice Managers prior to recruitment of anybody." (East Riding, Project Lead)

Sustainability by connecting with community groups

Some health champion groups are already connected to community groups and for some this may help with sustainability of the health champion work. The Singing for Health Group (Bradford) for patients with respiratory conditions had already combined with a Dementia Choir funded by the local Rotary Club and champions felt this would continue. The practice Walking Group has already combined with the Walking Groups provided by the local council.

One health champion from a small practice with little space and few champions felt that the health champion work could be continued at a local community centre.

"We were going to meet every Monday at the Community Centre just down the road and you can get a cup of coffee there, it's not very expensive and they have quite a bit going on as well in the centre." (North East, Practice Health Champion)

Practice attitudes to sustainability

Although all Practice Managers and GPs wanted the health champion work to continue there were doubts about its viability at the end of funding.

In the practice where the champions were forming themselves into a charity, they were unsure as to whether the practice wanted them to continue the work. In fact the practice was very happy for them to continue the work.

An important part of sustainability is the GPs and other practice staff referring patients to the health champion activities. There were various ways of promoting this suggested by practices. One GP suggested updated notices of group activities on the screen in the waiting area or on the practice intranet. A reception manager, who was to become the link in the practice for health champions, felt receptionists knew some of the patients quite well and would be able to suggest groups for patients where they saw a need.

One GP who was actively involved in supporting the health champions had not been aware when the funding was going to end. She felt it would have been better for the project team to work directly with the practice from the beginning so that they could work towards sustainability and she had no idea about how the work would continue.

A GP who had been supportive but rarely attended meetings was dubious about the health champion work continuing because the groups set up by health champions had not thrived.

"Should I be entirely honest? I think it will die. I think if you lose the project team and especially as none of the groups perhaps are hugely thriving." (East Riding, GP)

Another GP felt the health champion work would survive because of the commitment of the practice manager and the spectacular successes of the health champion work.

"I think because we've got S, the practice manager, I think it will, the momentum is there and it will continue, especially with the success we've had with the Christmas meal and the tea dance, our patient champions just want to do more and more." (North East, GP)

However, the practice manager herself felt it couldn't survive without finding further funding.

Nearly all Practice Managers felt that they could not prioritise the health champion work and without the support of the project team several of them felt that the work may not continue. The health champion work had already taken up more time than they had expected and they couldn't envisage taking on any more. One practice (Calderdale) said they would be able to do printing for the champions but not take on an organisational role. They described their stance as 'standing alongside the champions and helping where we can'. A receptionist from the same practice felt that there needed to be a person at the practice that the champions could link into but that it didn't matter who that was, just someone who wanted to do it.

There was however, one practice manager (Calderdale) who had already decided to give responsibility for the health champion work to another manager in the practice and was willing to fund successful groups, such as the diabetes group. He was also keen to fund a Walking Group if the health champions were willing to start one.

"The one diabetes coffee morning that worked, a young girl came in to see my diabetic lead the next week and went, "That diabetes meeting has changed my life totally because I wasn't managing it properly, I met all these people who have been doing it for years and it's already changed my life". ...So massive positive ...if they keep turning up, don't matter if the funding's there or not, we'll fund it, I've offered loads of money to fund it." (Calderdale, Practice Manager)

Another practice manager, aware that the groups weren't currently thriving, felt that the health champion work would be sustained through health champions helping the practice with the Friends and Family Test, signposting in the surgery and other events in the surgery.

Health champions take the lead?

Some practices felt there should be a 'lead' health champion who could liaise with the practice once the project team had gone. As health champions sometimes go on long term holidays or become ill, one health champion felt that the lead for the health champion work should be from within the health service. Another commented that she couldn't take the lead because she couldn't spell properly and because she couldn't afford the taxi fare to the surgery when her health champion friend was away for the summer months. For one person the thought of having to organise themselves was a bit daunting.

"It is a bit scary to be honest, it was nice to have someone there to kind of ask things about and maybe just, I don't know, not to do things on your own." (Bradford, Practice Health Champion)

"I'm confident that we will keep going, it's just the personal liability stuff that worries me." (Calderdale, focus group)

A practice operations manager (Calderdale) predicted that the health champions could organise their own activities once they had grown in confidence.

Training for sustainability

One champion felt that they should have been trained in ways to make the work sustainable, such as how to apply for small pots of funding, especially for those without previous experience of volunteering.

"I expected a little more direction and support because there were a lot of people who haven't done voluntary work or a lot of people didn't know how to approach it." (Calderdale, Practice Health Champion)

BARNSLEY HEALTH CHAMPION WORK

The health champion work in Barnsley was based around the theme of Pregnancy and Early Years. The work was slow to start with recruitment of project staff taking 6 months out of the 2 year project and early recruitment plans ran into difficulties and had to be redesigned.

Health champion activities were very slow to get off the ground but at the time of the interviews there were several activities providing help to women and families in pregnancy and early years.

Organisation of the health champion work

The Trust hosting the Pregnancy and Early years Project was happy to be involved with the health champion work because they were already considering using the health champion model at the time.

It was planned that the health champions would be recruited from and based in five Children's Centres. There were several reasons why basing the health champion work in Children's Centres seemed appropriate. It would give a focus and a base for the health champions and it could also connect them to the wider health system, and create in-built sustainability.

The NHS staff recruitment process for the project took 6 months and as the plan was to recruit 100 champions in the first 6 months, the project was already well behind when the project staff came into post.

There were concerns at the beginning that recruiting from this population may be difficult. The project lead, with extensive experience of community work in the area, felt that it would be difficult to find the numbers required and wondered if they would find health champions that could act as role models for others.

"When you're recruiting from children's centres that are based in the most deprived areas of an already deprived town, that's a hard target to reach, 20 in each children's centre is a hard target to reach and you know, are those 20 people going to be the right people kind of thing." (Barnsley, project lead)

Despite being aware of the potential difficulties the Trust felt it was worth the attempt to get people from these communities involved.

"They've obviously got quite... complex disorganised, chaotic kind of lives, they're not necessarily in a position right for volunteering for anything and I think that's obviously, you could have said we knew that from the outset, that these were going to be difficult people to get involved and trained but people who are going to children's centres anyway, if they're going there anyway, so there was that thought, if they were going there anyway, just need to extend the thinking and get them to

come together for all kinds of volunteering reasons, might just work." (Barnsley, Trust director)

Only a few health champions were recruited through the Children's Centres.

The Trust director also felt that there was some misunderstanding on the part of the Children's Centres about the nature of the health champion work. They felt they would have to find work for 20 volunteers, rather than the health champions creating their own work.

"I think as the children's centres got into it, they said "I'm not sure I know what to do with 15 health champions", I think they missed the point around some of that but I think basically it became a struggle to get the numbers for individual centres." (Barnsley, Trust director)

At the same time the future of the Children's Centres was under threat so working with health champions wasn't something they could focus on.

"And of course the children's centres had their own, starting having their own huge agenda about their ongoing viability in the future, so they're currently in a huge review, by which you're going to lose most of them, so it suddenly wasn't the main issue on their agenda." (Barnsley, Trust director)

There were also concerns about governance and whether the health champion work was a substitute for paid employment.

"They started to get very worried about the whole thing about CRBs and all governance stuff, about what people were doing and, was it actually paid employment through another route, all that kind of stuff, some of them started to get somewhat angst about all of that." (Barnsley, Trust director)

Having not been able to recruit from Children's Centres and being very behind on achieving recruitment targets the project team started to recruit from other areas on the Barnsley community, in particular young people in the local college. Consequently, the health champions are from all over Barnsley area and have no base in the same way as champions in GP practices in other health champion projects.

Additionally, there was a considerable amount of organisational change in health services during the lifetime of the health champion work.

"My role has changed since I first started coming to the events as well, so the service I was with got decommissioned and I've been absorbed into the 0 to 19 service. So my role and remit has changed." (Barnsley, senior NHS Manager)

Activities

There is a core group of approximately 15 active health champions running groups out of the 100 recruited and trained.

Baby Basics

The Baby Basics group work in conjunction with the Salvation Army. They provide Moses baskets full of items for a Mum and her new baby, for women who find themselves pregnant and in difficult circumstances. They provide items such as baby clothes, bedding, nappies and bath time items for both Mum and baby. They work in conjunction with the maternity unit and health visitors both of whom can refer women for the Baby Basics packs.

Clothes banks

There are currently two Clothes Banks and a third is being planned. The Children's centres received a great deal of clothes donations and they haven't the time to sort and package them. The health champions sort and package the clothes and help with the distribution of these at the Children's Centre.

Knits and Bits

The Knits and Bits group was launched by a health champion to encourage older people to come and teach younger women the arts of knitting and crochet. Although her main aim was to relieve the isolation and depression of older people, the group knits items for the Baby Basics pack and for the Clothes Banks. They had a successful Facebook group where people exchanged patterns and people posted requests, such as items for a young Mum who had lost everything in a house fire.

Bright Sparks

The Bright Sparks group was developed by two health champions who have children with additional needs. They felt there was a need for a group in their area which included children with any disability and their whole family. Most groups cover children with a single diagnosis and are often just for the child, not their siblings.

Women's Coffee Morning

One health champion, from an ethnic minority group was in the process of setting up a Women's Coffee morning aimed at women from ethnic minorities. As there are few ethnic minorities in Barnsley the health champion knows that they can feel lonely and if they are

new immigrants they can find it difficult to get information on what they need to do or any help available.

Pregna Buddies

A health champion is developing a scheme called Pregna Buddies to provide companionship for pregnant women who are on their own and attend hospital appointments with them if they wish. Such a scheme is complex and it is taking some time to lay the ground work. The health champion who initiated the project is frustrated and doesn't understand why getting the scheme off the ground is taking so long.

Health Champions Benefit

The groups in Barnsley had been going for only a short while at the time of the interviews (June 2015) and already the health champions were beginning to recognise the benefits of being involved. They enjoyed the groups and had a sense of achievement from helping others.

"I do think it's a really good idea and it's really good to have and I do absolutely love it...Gives you a purpose in your life doesn't it?" (Barnsley, focus group)

"Meeting other people, the groups as well, even though they've not progressed further but I think it's a good thing for the community of Barnsley." (Barnsley, focus group)

One health champion who started the Bright Sparks group gained a sense of achievement as well as improving her and her family's well-being by providing a place where they could all feel relaxed and less isolated.

"It's like a sense of achievement in a way. It's like doing something nice for other people. It makes you feel a bit more relaxed that your child's going to be playing with other children who have other needs and you don't feel isolated. Because obviously when they get a diagnosis, it's like... go and find whatever you can to help but they don't really point you anywhere." (Barnsley, health champion 2)

The project lead noticed the growing confidence in some health champions and how the confidence allows them to take part in more activities

"When she first came to the training, she wouldn't speak to anybody, she struggled to even introduce herself because ... she told me she didn't like talking in groups, really low confidence and is now leading groups on herself, doing all sorts." (Barnsley, project lead)

Participants Benefit

In the Knits and Bits group the health champion running the group noted the impact on her own mother. By teaching others to knit and knitting for the Baby Basics pack knowing she's helping mothers in difficult circumstances has made her feel valued. Another older lady had gained the confidence to come out of the house as a result of becoming part of the group through a friend.

"It just gives them a purpose, they've no confidence, the people that are stuck in their house, day after day... they get so depressed, I mean my Mum has gone through some depression but this has given a purpose, it's made her feel as though she's wanted." (Barnsley, focus group)

"She hasn't got that confidence to get out of house and do things but because J lives round corner from her, it's her that's encouraged, "Will you run me down to this school?" and she's got her involved in that. So getting her through the door has been an achievement." (Barnsley, focus group)

The Bright Sparks group provided a place based around the needs of both the child and the family, rather than a condition.

"From my experience, when my son was diagnosed with autism, you'd got a lot of autism, Asperger's groups out there. You hadn't got that many that cover all the additional needs, whereas we do, we have any children with additional need, not just the autistic ones." (Barnsley, health champion 1)

"My son at the moment doesn't have a diagnosis of anything, we're just in the middle of that process but he has a lot of behavioural problems and for me, it was somewhere that we could go, even though we didn't have a diagnosis, where there was other children with the same but then we also wanted it to be open to the families as well, like my older daughter goes and that's nice for her because she gets on well with Z's daughter and they can play normally, ... and the parents would come and know that people aren't staring at their children when they're having a meltdown in the middle of the floor, ... it's just somewhere that you can come and play and have fun without being judged." (Barnsley, health champion 2)

One of the participants, with four children, three of them with additional needs, had hardly gone out in the past but the group allowed her to relax with people who understood her experiences.

"So she said it's nice for her to be able to go somewhere and not be judged, just know her children are okay playing." (Barnsley, health champion 1)

One of the health champions explained that siblings often feel they have to 'look after' the child with additional needs and can be worried about their behaviour but in the Bright Sparks group the siblings can relax and play.

"So it's nice there because they don't have to do that, they know that it's okay, "Adam's playing so I can do something over here", and I think also she gets a little bit embarrassed sometimes at some of his behaviour and she doesn't feel that there because they're all doing it." (Barnsley, health champion 1)

The Clothes Bank and the Baby Basics pack groups don't have 'participants' as such but the benefits to families in crisis was clear to a health professional. She also reported how useful it was for health professionals to be able to refer their clients to these services run by health champions.

"Certainly from a health professionals' perspective, that is fantastic, having somewhere we can go when families are stuck and in crisis and can't afford the basic requirements that they need, when they're pregnant or just found out they're pregnant, that is fantastic and then obviously we've got families who have 4 or 5 children and to be able to afford the clothes and children grow out of clothes so quickly, so it is a fantastic recycling, upcycling model, that... certainly the people, my colleagues who have used it have found it really invaluable for the families they're working with." (Barnsley, senior NHS manager)

The Head of the Children's Centre, which hosted a Clothes Bank, reported the additional benefit of being able to register the people who came to the centre and inform them of other opportunities at the Centre that might be helpful to them.

"We get a lot of people coming through the door who we don't know so that's good for us because obviously we register them to the service, they come in and they get the clothes that they want, so in a sense, for us, we are seeing people who we've not got on our database." (Barnsley, Head of Children's Centre)

Support from the Project Team

As with other health champion work based in GP practices, some health champions were surprised that they were expected to come up with ideas of groups they wanted to run rather than just being able to join an existing group and helping. When they did start a group they felt there wasn't enough support from the project team to get things going. They felt isolated and without direction.

"I never expected coming with an idea and expected to run with it myself, you know, without any support from them, I expected somebody to be there because I knew that I wouldn't be able to commit to every week and they've known that from the word go because I've not been able to get it up and running because I've been on placement." (Barnsley, focus group)

"I think it's what I said earlier, they've done this training and with the promise that, "We'll be there to support you" but then nobody knows where to go because we don't really, other than them saying "We've got this training on, do you want to

come and do this training?", we don't really get any other sense of direction, so we don't know." (Barnsley, focus group)

One health champion had not joined the health champions to take part in Pregnancy and Early Years work. Her interests were in mental health and so she was directed by the project team to volunteering with MIND. She had little contact with the project team after that.

The health champion who was developing the Pregna Buddies scheme was very disappointed to find that the training on confidentiality and other issues necessary for the scheme had been arranged for a day when she was in college. The health champion involved feels that the scheme has now stalled.

The health champion running the Knits and Bits group ran the group on her own and as she was about to go on a placement for her nursing course she was worried about who could take it over for her. (A health champion offered to step in at the interview) She also felt she needed support when people mentioned problems on the Knits and Bits Face Book page.

"I think we could do with being a bit more informed about some of the groups and things and who to contact when somebody comes on Facebook and says, "so and so's happened to this person", so we could direct them to other people." (Barnsley, focus group)

There was a different perspective from professionals working with the project. The Head of one Children's Centre invited the project lead to join the Board because she found her experience and knowledge to be very helpful, and an NHS senior manager felt champions were well supported.

"The project team are fantastic and really passionate and motivated, I've worked with (project lead) and (project worker) before so, in terms of them and their support that I've seen to the health champions, it's been excellent." (Barnsley, senior NHS manager)

Whole System Events

There were five Whole System Events (WSE) in Barnsley. The first Whole System Event was preceded by several design meetings to establish the topic to be discussed by those in Barnsley with an interest in Pregnancy and Early Years, both professionals and the health champions.

Members of the design group for the WSE felt initially unclear as to what they were trying to achieve and as a result some people left. Some did, however, return for the WSE.

"I think when we first started in the design group, I think maybe that's part of the problem, is we didn't know what we were setting out to achieve, it was all a bit

vague and a bit wishy washy because it's about it being driven by the volunteers. But some of what was being said in those design groups was that the health champions would be part of the health team and be sustained then ongoing within the health team and I know that hasn't happened." (Barnsley, Senior NHS manager)

"In fairness, the first couple of sessions was a bit kind of, everybody was not sure where it was heading and the purpose was a bit blurred, it wasn't very crystal clear from the start but as it went on, ... it got a little bit clearer and clearer and clearer but you know, they were well organised, well delivered, no problems with them." (Barnsley, Home Start)

"I went to three or four meetings and it sounded like a dream, it was like this vision and I was thinking 'how is this going to work... where's the time and where's the money going to come to do all these things?" (Barnsley, Community Midwife Team Leader)

There were 85 attendees at the first WSE. The participants included chief executives from the South West Yorkshire Foundation Trust, the local authority, the CCG, the hospital Trust and third sector organisations. There were also middle managers, midwives, health visitors, health champions and citizens. Out of approximately 100 trained health champions there were approximately 30 active champions and 15 attended the first WSE. The Trust director thought that absence of the health champions may have been due to not seeing any link between the WSE and the health champion work they were doing, and that attending meetings with senior professionals was not what they wanted to do.

"I think that's why champions are not necessarily that bothered about the Whole Systems Event because it doesn't particularly relate to the stuff that we've asked them to get involved in or are interested in getting involved in local communities, just coming to a thing where they talk about some whole system change thing. That kind of stuff attracts a different kind of person, I'd suggest, to the ones who want to get on and do something with a children's centre. If people want to come and talk to a chief executive about some big issue, they're a different kind of being aren't they?" (Barnsley, Trust Director)

The project lead also felt that health champions didn't attend the WSE because they couldn't see the connection between the health champion work and the WSE.

"Obviously the whole systems events are a slightly different thing in that they're there to change the system as a whole but they're there to kind of get that co-production going on, so to take on board the views of the champions and stuff. But we have struggled to engage champions in that because they don't see how it affects them and I think that's difficult to get across." (Barnsley, project lead)

The health champions who did attend the WSE, however, were enthusiastic about the experience and possibilities.

"When we went to the Metrodome group, 'how to do the best start for children in Barnsley', that was amazing, all the things that come up in that group and when you're working with all the different other professionals that are in Barnsley because there were people from Home Start, people from council, children's centre staff, there were loads of different people there and it were just really, it makes you feel like you can do something to change community and make it better for people, I just love it, me!" (Barnsley, focus group)

"Yeah, it was good, you felt as though you were involved with quite a big project didn't you and... you get a sense of, "Actually I can do something about what's going on in the system"." (Barnsley, focus group)

One champion, however, expressed disappointment that the health champions had not been fully involved in the event, in their view.

"Yeah, that one was good but obviously nothing came out of it. As volunteers, I think we should be involved, they should involve us as well as involving the professionals, it shouldn't be just at the back with just professionals talking without involving us." (Barnsley, focus group)

The project lead did feed the champions view back to the Altogether Better team but presenting what the health champion were not considered appropriate for the WSE.

"We didn't talk about what we were already doing at all, at any of the meetings and again I did raise that and at the last one we had, the last whole systems event, S and I suggested doing a bit of a showcase about what champions had been doing and were told that wasn't what the whole systems events were for, so we didn't do that." (Barnsley, project lead)

The health champions, however, did feel they could progress their ideas through meeting with health visitors and midwives at the event.

Two main ideas came out of the first WSE meeting and they were ambitious; (1) a town centre hub where parents could go for several services relating to early years and (2) a database with information on everything that was available in Barnsley to support families with children under 5 year old. The project lead didn't think either of them was feasible and one of them, the database, she said had been tried before and failed.

"In my opinion, I think some of those ideas were massive, they were too grand, like the two main ideas that came out of that idea were [1] people wanted a town centre location where it could be like a one stop shop for everything you wanted to know about pregnancy and early years, the second thing was a database or an online tool where again, you could go on and look at everything there was available in Barnsley. Those two things were never going to happen because we're in the third or fourth year of massive budget cuts in Barnsley." (Barnsley, project lead)

Participants of the first WSE were very enthusiastic about their ideas but eventually the political environment posed major barriers and the project lead felt they became disillusioned.

"The issue of "Where's the money going to come from?", they felt like they personally couldn't do anything because they were already having budget cuts, they were already being asked about why they were spending time going to these meetings when everybody was being scrutinised because they had a massive restructure." (Barnsley, project lead)

A local councillor was very hopeful that the event would promote change but she was disappointed that other local councillors did not show any interest in the work.

"I thought it was innovative, had great hopes of it ...It was about engagement and communication, which is not something that we get a great deal of, in any forum, as being elected members, I tend to find that everybody has got an empire and they're defending it and I thought if we can get all these people in this room engaged and prepared to do something, we could initiate a change...I thought it went very, very well, I was very optimistic when I left the meeting. I did try to get my local council to perhaps take it into council for all councillors to be part of it, but no takers." (Barnsley, local councillor)

"I went to the first one at the Metrodome. I thought it was good, it was a real eye opener for me, considering I've lived in Barnsley for the past 23 years, to see the extent of the health inequalities and the fact, I mean my background is NHS, because I became a minister, I was a midwife and... we tend to work in silos and people don't know what other services are happening and able to provide, I think there's a lot of lack of knowledge. In terms of networking, in terms of getting your, not necessarily your own project but knowing what other people are doing and what kind of things you can access, I thought it was great." (Barnsley, Salvation Army)

"I thought it was good and it was enjoyable and we got a lot out of it, I really liked the way they recorded it and the pictorial way. Personally, I didn't feel it told me anything I didn't already know as to what the issues in Barnsley are but it was good in raising that profile to some other partner organisations and certainly, some of the councillors and people like that because I think services exist and people don't always know what they do and the issues people are facing on a day to day basis, so I think some home truths came out of that and it was good at getting everybody on board and engaging people into the process." (Barnsley, senior NHS manager)

The networking at the event proved invaluable for one health professional who appreciated the time to focus on learning about what was available in the town.

"I've learnt so much with the networking....you know what's happening with women whose partners have come out of the army and things like that... I've learnt so much regarding the networking definitely. It's what's on the landscape, it's what in our town that we didn't know about." (Barnsley, Community Midwifery Team Leader)

The number of participants dwindled after the first event and one participant thought this may have been due to the unstable job situation of many of the participants and difficulty of getting ideas accepted in their organisations.

"I think a lot of reasons, it's probably people's time, I know that a number of people who were at the initial ones were fearful of their own jobs, so they might not have been in post, so they're dealing with their own, that as well. I don't know. I think with a lot of these things, things sound good in theory but it's how do you instigate that and how do you then communicate that to the decision makers, the permission givers within your organisation?" (Barnsley, Salvation Army)

The Health Champion Model in Barnsley

There was still some confusion at the end of the funding about the nature of health champion work and the link between health champion activities on the ground and the role in the health champions as change agents with services.

"I still think there's some uncertainty and what it is about anyway, I do think there is something about that. It is far more - and I think there's some learning from that - I think where Altogether Better are at now, from the projects and what they feel health champions are about - is in a different place than when we started...I think it's become a lot more about a general sort of engagement, empowerment model than it is about necessarily, I guess champions, the kind of peer support models and champions doing things, tangible things." (Barnsley, Trust director)

"Well I don't know how we ended up with that position, that this is somehow about forming a big question but that's very much about that engagement, seeing the champions as a change agent in terms of that systems thinking, but that's really different to kind of changing the system at a grass roots level and changing it by virtue of the nature of the work you're doing." (Barnsley, Trust Director)

Sustainability

The project lead has been funded by South West Yorkshire Foundation Trust to continue to support the existing projects for 12 months. The support will not be available full time however, as supporting the health champions will only be part of her remit.

The health champions had only just been made aware of the ending of funding and they were worried about the future of their groups.

The Bright Sparks group, however, had already made themselves into an organisation that could apply for funds locally. They had experience of doing this in another group they belonged to.

SHROPSHIRE YOUNG HEALTH CHAMPION WORK

Organisation of the health champion work

The work was based in the Clinical Commissioning Group (CCG) and supported by the GP lead. The project lead had previously worked in Patient and Public Involvement in the local Trust. The young health champion project commissioned youth workers from the local authority to undertake the support of the Young Health Champions. Given the age of the Young Health Champions (11 to 25) this was important for safeguarding as well as support. During the time of the project the health champions have revealed difficult circumstances to the youth workers and they have been able to put safeguarding measures into place.

To ensure that local organisations knew about the health champion work in depth, the project lead invited representatives of the organisation onto a 'train the trainer' event, although it wasn't intended that they deliver any of the training. The project lead felt that this was a very successful element of the health champion work. It directly led to connections between the Life Lessons (Death Education) tutor and the police force who part-funded the three courses that were delivered.

"I went to a special young health champion youth worker training course and it just so happened that I was sitting next to... the Commander of the Shropshire West Mercia Police Force and he was on my table where we did all the interactive exercises and we were really getting a lot out of it...he said "We have young offenders that could really benefit from this", and I knew already that 10% of the young offenders were in the court system because of a bereavement, they went off the rails, they got angry." (Shropshire, Life Lessons tutor)

During the time of the project the local authority were in the process of decommissioning the youth work. The re-funding of the work by the CCG (see 'Sustainability') has enabled the continued employment of the youth workers in the young health champion work.

Activities

The GP lead of the Clinical Commissioning Group (CCG) was key in bringing the health champion work to Shropshire based on her previous work with young people in reducing the teenage pregnancy rate. The work of the health champions has far exceeded her expectations both in the nature of the individual projects and the maturity of the approach of the health champions in their concerns about health and well-being issues beyond the teenage population, such as preventing type 2 diabetes, or becoming Dementia Friends.

"So again I suppose I had underestimated, hugely, how sophisticated the youth of today are! When I was that age, quite frankly, did I really worry about whether I got diabetes in 20 years?" (Shropshire, CCG GP lead)

She was also impressed by the number and commitment of the Young Health Champions which she felt demonstrated a vast untapped need for young people to make a difference to their community.

"I've been massively impressed and as I said, they've well exceeded my expectations, I suppose on two fronts, firstly the sheer number of them, the complexity and detail to which they've gone into these projects in, so it hasn't just been a superficial kind of approach.... I think this is probably the most telling and it probably has identified what was a huge unmet need in our community." (Shropshire, CCG GP Lead)

The activities described here are the ones that were current at the time of the interviews (April 2015). A full list of activities of the life of the project are available in other sections of this report)

The Teen Room, Telford Hospital

The Young Health Champions were approached by the director of the local hospital Trust at the Whole System Event to help with the design of a room for young people in the new paediatric ward. The health champions were involved in all aspects of the design and on the 'rules' for the room. They had to learn about infection control and other aspects of design in a clinical environment.

The Trust director and health champions also intend to work on a film charting the journey of a patient through treatment in order to illustrate the range of careers available in a hospital.

Diabetes Film for Teachers

Two young heath champions with diabetes had considerable challenges at school getting both teachers and pupils to understand their condition, such as why they may need sweets before a sports activity. They decided to make a short film on You Tube educating teachers about the condition with the help of a diabetes specialist nurse. Out of this project has come a different project aimed at educating young people about Type 2 diabetes and the importance of healthy eating to prevent Type 2 diabetes in later life.

Life Lessons - Death Education

Young Health Champions were given the opportunity to take a course on death education. This was designed to put death in context globally and to allow the bereaved to express how they feel and remember the person they have lost. It is designed to break the isolation some young people feel when they have been bereaved. It was a popular choice and the lead from the organisation providing the course ran three courses for the health champions and young people who had been bereaved in Shropshire schools. The course was part

funded by the Police and Crime Commissioner in recognition of the role bereavement sometimes plays in a young person's criminal activity.

Welcome Initiative in a GP surgery

A GP requested help from the Young Health Champions in creating a welcoming environment for the young people in their practice. They recruited Young Health Champions from their own practice population. Twenty two young people did the health champion training and 6 have become active in the practice. The rest went on to join other health champion projects. The champions in the practice have embarked on a process of suggesting changes, such as having a noticeboard just for young people, and also explaining to staff how a young person feels when coming into the surgery. Another surgery has now also asked for Young Health Champions in their surgery.

Happy Schools project

The 'Happy Schools' project was suggested by school nurses who were concerned about the stresses and bullying in schools. The Young Health Champions also felt there was a need for a 'Happy Schools' project. This hasn't worked out as planned yet but there have been some projects coming from young people attending the project groups in schools. Transition to secondary school was identified as a stressful time and the health champions have made a film for the school website to introduce newcomers and they devised a buddying system and activities for new pupils. In another school the group are organising a fundraising event in memory of a pupil with muscular dystrophy who passed away.

Young Health Champion Shop

The Young Health Champion shop in the centre of Shrewsbury provided a focal point for young people in the town and from outside the town. It was just a place to hang out and various activities could take place there. A youth worker attended. Sometimes it was packed, other times there was hardly anybody in. The lease has run out so the Shop will shut but it has proved such a need that a town centre church has offered its premises for the activity to continue. The rooms available are large and health champions will be able to hold many more activities there.

Future Fit

The Young Health Champions are asked regularly by local health services for their view on health service provision. There is soon to be a consultation, Future Fit, on major reorganisation of services and several Young Health Champions have been trained by the project lead to understand the issues and to develop the confidence to speak on them.

CCG Takeover Day

Last year the Young Health Champions took part in the 'Takeover Day' at NHS England; a day when members of the public drive the agenda for discussion on health services. Later this year the Young Health Champions will take part in Takeover Day organised by the local Clinical Commissioning Group.

Educating Paediatricians

A young health champion with Cystic fibrosis had an upsetting experience when she was young in a clinical consultation. She has made a film educating medical staff about how to approach young people in consultations. It was launched at the Royal College of Paediatric and Children's Health to an audience of 1,500 and has been viewed many times on You Tube.

'What the Chick is That' cookery classes

'What the Chick is That' is a cookery project initiated by a young health champion studying for a catering qualification. He wanted to help people using food banks on how to cook cheap nutritious meals. The title comes from a common question at food banks querying what chick peas are. At Christmas the health champion ran a course on Christmas cooking for care leavers. The project went into hibernation and has now been revived due to the interest of a local cookery book writer who is passionate about young people learning to cook.

The Mission Impossible transport project

The Mission Impossible project is a research project undertaken by the Young Health Champions on public transport in Shropshire. They are feeding back to the transport companies the views of young people on the services. At the same time they are educating young people on travelling on public transport so they will feel more able to go out and join in the activities available to them.

Orthopaedic Hospital

Young Health Champions are helping the orthopaedic hospital in Shropshire to gather the young person's view of services and to include their view in the re-design of services.

'No Panic' helpline

One young health champion with anxiety disorder wanted to find ways of reducing anxiety for young people. She found a helpline, No Panic, for people with anxiety disorder but they didn't have a helpline for young people. The organisation said they could set one up for

£1,000 and so she set about putting a concert on to raise the money. They raised £1,600 and there is now a helpline for young people with anxiety.

Health Champions' Benefit

The two major benefits for young people of being involved in the young health champion work have been a significant growth in their confidence and the mutual support they have given to each other. The benefits have been recognised by the Young Health Champions themselves and the professionals involved in the work.

The project lead and youth workers also explained that Young Health Champions like the responsibility that is part of their role as a health champion.

"They like the responsibility, they feel, I suppose empowered is a youth work word, they do like the responsibility and some of them have had their own projects that have evolved from ideas that they've had and we've been able to take that forward. But it's something different isn't it? It's all fun activities, it's not like school and they have made a difference." (Shropshire, youth worker)

They also pointed out the benefits of the Young Health Champions having a friendship network separate to their school life.

"I think because some of the young people, their social networking is just around school and some of that can be quite destructive and we've seen young people come out of that and start mixing with different ages, different young people and now they have another social network that is really affirming." (Shropshire, youth worker)

The examples given below represent only a small fraction of the enormous health and well-being benefits produced through the health champion work.

A young person with disabilities previously lacking in confidence has been able to say how he feels as a result of becoming a health champion as well as being able to fulfil his ambition to help others.

"It's been really hard for me to say how I feel to people because I used to be so shy, I used to be timid but now, because I've joined the health champions, I've become more open about my feelings, how I feel about things, and I'm happy that I've done that because I can really come out and be myself all the time now because I want to help young people, it's what I've always wanted to do."

He said that being a young health champion has expanded his experience and opportunities.

"Meet new people, learn new things, go to new places...I'm really grateful I've joined health champions, it's the best thing I've ever done in my life." (Shropshire, health champion)

Another young health champion joined because she wanted to help other people and she thought it might also help with her confidence. She has Cystic Fibrosis and never spoke to anyone about it. She had also experienced an event in a medical examination that had upset her. Now, as part of the health champion work she has made a film for medical staff about how to approach young people in consultations. She's also made lots of new friends and has not only grown in confidence but developed more empathy for others.

"I used to feel that I was different to everyone else and through this I realised that other people had similar things to me, I know it sounds a bit weird but I just didn't feel the same, ... a lot of health champions have a lot worse than me so it made me put a bit of perspective on it... I've learnt to be more empathetic to people... If someone's upset you can sit and chat to them, I learnt that through this....I've got a lot more confidence, like I wouldn't have told you that I had CF, I just wouldn't talk about it... but I feel I can talk about it now.." (Shropshire, health champion)

A young health champion with diabetes gained the confidence to be away from home through being a health champion and even though her first trip away ended in a hospital stay, she's still maintained her confidence.

"I'm a lot more confident in myself, I didn't like leaving the house much around town because I was kind of scared about trusting myself and my diabetes but now, I was able to go to Birmingham with friends and trust myself, but things didn't go so well because I left my diabetic stuff at home, I had to have a day in hospital....I'm going again in November, going to try it again and hopefully I'll remember it, my mum will probably pack my bags!" (Shropshire, health champion)

She had also previously been lacking in confidence to make friends but now, as a young health champion, she not only had confidence but a group of close friends to support her.

"Now I'm in this group of really close friends, there's about nine of us and it's so great to have a group of friends who you can trust and talk to whenever you need to." (Shropshire, health champion)

The project lead noted the growth in confidence in one young health champion who suffered from anxiety disorder.

"The sense of pride she had in it and what she had to overcome to do it because she suffers with anxiety disorder, she was very good friends with the lady who died from a diet pills overdose and she died a week before C's big event and so C not only had to deal with her anxiety about this event, she also had to stand up in front of people and she wanted to dedicate the event to her friend that passed away and so all of that, watching her overcome it all and succeed, it made a huge difference to her." (Shropshire, project lead)

One young health champion with disabilities developed the confidence to go out to a shop on her own.

"When we did the last Mission Impossible session, we sent her to the shop just to get a packet of sweets for a game and after the session, her dad came to pick her up because she doesn't go anywhere on her own and she told him and that was the first time in her life she'd ever been to a shop on her own. Something so simple but her dad said he was amazed because she wouldn't have had the confidence to do it, so it really did make a difference to her." (Shropshire, youth worker)

As well as confidence and support, the Young Health Champions also gained valuable life skills. One young health champion as a result of speaking at an NHS conference became more aware of what he was capable of and he grew in confidence.

"It taught me how to paraphrase ideas and feed them back, not just an opinion, which is a very important skill and I've used that quite a lot." (Shropshire, health champion)

Other skills useful for adult life were gained by the Young Health Champions involved in designing the young person's room at the local hospital. They had to consider the design within the context of what was feasible, for example, choosing materials that were resistant to infection.

"An opportunity for transition and for a level of responsibility as well, it's very easy in this day and age to be a bit sort of mollycoddled, lots of kids staying with their parents longer than ever before, so how do you take those steps into adulthood?" (Shropshire, Trust director)

The Police Inspector involved in young health champion work noted how confident these people were.

"They are confident, used to speaking publically. Obviously it's something that has gripped them and empowered them....a quite impressive group." (Shropshire, Police Inspector)

The diabetes nurse involved in helping with the diabetes film for teachers reported that there was an unexpected benefit for the two Young Health Champions. As a result of having to explain to others about the condition they started to pay more attention to their own health.

"Two of the girls took more notice of their diabetes, started to think about it more, about what they are doing ... because they were going through that process of what they should be telling other people." (Shropshire, specialist diabetes nurse)

The project lead commented on the life skills benefits of becoming a young health champion and the CCG GP lead noted the increase in mental well-being.

"I'd say all of our health champions are really employable young people who have realised that they have the power to make a difference, they have the power of change and that's the best bit of it, every single time." (Shropshire, project lead)

"So I think that's the main thing for me, has been the mental health aspect of this, there's been all sorts of things about healthy choices, lifestyle choices, the diabetes project ...so it is that mental resilience that I've seen come through, particularly knowing some of them and where they've grown to." (Shropshire, CCG GP lead)

Participants Benefit

The Life Lessons course on death was chosen by the Young Health Champions as a course they wanted to do. It was open to others besides the Young Health Champions. It produced enormous benefits for some of the most challenging, bereaved young people taking part. The course was over 3 days and the schools were so concerned about these young people that they were allowed to attend the course during school time. The results were astounding.

"I had children that were very disruptive in class, that had severe anger issues, breaking their arms trying to knock down a door at the school, that sort of thing and when they went back, the one that had been purported to be so angry, was calm, calm and compassionate and kind to others." (Shropshire, Life Lessons tutor)

"The one I was told he had severe attention deficit, would be bouncing off the walls, would be super disruptive, he came back and he was focused, doing his work, that happened, these transitions that I'm telling you happened within 24 hours, first day because I took them right to the heart of what their issue was and I let them talk about it. But I also taught them healthy ways to talk about it." (Shropshire, Life Lessons tutor)

The Life Lessons course also helped in family relations.

"One mother reported that she had had the longest conversation that she'd ever had with her son, he was 14 and she said "one night we just stayed up until 1 in the morning talking about the death of my mother" and how they bonded over that experience." (Shropshire, Life Lessons tutor)

Sadly, the learning from the Life Lessons course were needed as a result of the death of one of the health champions and then a second death of a friend known to health champions. What they had learned helped the health champions cope with the tragedies.

"We brought all the health champions together and we did all the exercises with J and we did some counselling and then of course by the following weekend, the second young person had died and the group that she was engaged with, with the Youth Service, they brought them all together on a Sunday evening for a meal, to chat and talk about how they feel and the youth worker who isn't one of our team, reported back that L had outshone the youth workers in his counselling skills and he was the one that suggested they started a memory box and he was the one that said,

"What would we write to C, if we could still see her now, what would we say?" and he was putting all those things he'd learned into place." (Shropshire, project lead)

Whole System Events

There have been 2 Whole System Events in Shropshire bringing together the Young Health Champions, the fire service, the police, Shropshire Council, Shropshire Community Trust, the CCG, working together to focus on the creation of services that young people need.

The project lead explained the planning of the event and the health champion work which came out of the events.

"We got together a core group of what we call key local leaders who sat down and were part of the... five or six planning meetings with those people, who helped to decide what it was we were going to ask when we were all together, who were we going to invite, where was it going to be, what was the right times to have it and so even the system leaders were involved together in the planning and the invitation list, so you get all this rich information into the planning. ...And it did, it worked. The follow-up event wasn't quite as successful in terms of attendance but to be honest, I don't think it mattered a great deal because we'd already got two or three really good ideas, the safety champions is one, there's a school now working on a transition project, so how you help children from Year 6 transitioning to Year 7, emotionally."

It was a pivotal moment for the police inspector who attended.

"You know what it was one of those events which sticks out from the last years to be honest and it was great to meet with a bunch of really motivated kids, and there were kids there from the school on one of our largest estates, and the school purposefully sent some of..... the ones with behavioural issues, and I found them to be fantastic, and it gave me a real boost in me wanting to work with the Young Health Champions." (Shropshire, Police Inspector)

The Governance and Involvement lead from the CCG expressed how the Young Health Champions made her think differently about services and how focusing on the Young Health Champions was a powerful way of bringing services together.

"I found them really creative and beneficial and made me think in a different way, as a person as well. The opportunities of using the young people as a conduit to join up agencies working together are immense. It's really powerful." (Shropshire, CCG Governance and Involvement lead)

She also commented that it was a challenge to bring everyone together in terms of the same mind set.

"...with our thoughts and mind-sets but that's going to be the norm in any situation like that. But certainly it didn't faze me or (GP lead), we just got on and we did stuff

and sometimes you have to work around people to get the work done." (Shropshire, CCG Governance and Involvement lead)

The GP lead for the CCG did not want to be too visible in the Whole System Events because she felt that her presence would stifle the discussion.

"I stay very much out of the kind of designing, structuring because I knew the moment that I step in a room, even if I make some really random suggestions, they become set in stone as this is the thing we must do, it must be right and I absolutely hate that! Quite frankly, let's be honest, if I had the answers, I would have done it, yes?!" (Shropshire, CCG GP lead)

The fire and police service were planning to develop a scheme to warn young people about the dangers on the streets. The Young Health Champions told them what they were really worried about and it was an 'eye opener' for the services.

"One particular table had police, fire and young people sat on it and they started talking about, well, the police were talking about safety in terms of stopping yourself being mugged or really quite brutal things and the fire were talking about quite extreme things and the kids on the table said, "Actually, we just want to know how to be safe when our Mum and Dad are out of the house" and the police said it was a bit of a wake-up call, they said you always think about the big crime stuff but what the kids were talking about was probably the bulk of figures which are just smaller, some people might call it petty crime but it's significant to those young people." (Shropshire, project lead)

The health champions are now working with the Fire and Police Service to develop a Young Safety Champions scheme in which the Young Health Champions will help to design and deliver the training on safety in the community.

System Change

The Young Health Champions are beginning to make a difference to several organisations in Shropshire and those organisations are changing their way of working to include the ideas of the Young Health Champions.

The Shropshire Clinical Commissioning Group include the Young Health Champions in many aspects of their organisation. It has changed how they think about commissioning all services, not just those for young people.

"The other thing for me with working with young people, it really provides a different insight in how you commission services because you're not thinking of commissioning for now, you're thinking about what will the young people now need in 20 years' time. So it has changed how we think around commissioning." (Shropshire, CCG Governance and Involvement lead)

The Governance and Involvement lead explained how the Young Health Champions were influencing policy making.

"Working with the young people just adds, seeps into other streams of work but it just ... it's organic, so it's just seeping into stuff, I can't quantify that view but I know certainly the Better Care Fund (with the local authority), I know it's a piece of work around ageing population but we're asking young people, thinking about how this might have an impact on them when they're older." (Shropshire, CCG Governance and Involvement lead)

The involvement of the young people in the commissioning of services required sustained work from the organisation but the investment was well worth it in the eyes of the CCG.

"It's just a real privilege I would say, you have to invest the time, you have to be committed and you've got to believe in it but the payback you get is just amazing. I would recommend, even if you do it on a smaller scale, is having those sustained relationships with the young people, that you don't pick up and drop off... that it's a continued thing, the pay back is huge." (Shropshire, CCG Governance and Involvement lead)

The Clinical Commissioning Group have agreed to fund the health champion work for the next 12 months and they see their investment in terms of the creation of resilient communities which eventually could save healthcare costs.

The director of the local NHS Trust also described the added value of having the Young Health Champions involved in their organisation.

"They see pictures of joy and engagement and creativity and that reminder about, our jobs in the NHS risk being quite sort of, they can be a bit bureaucratic and dealing with the bureaucracy of the requirements of the NHS and it is so Goddamn enriching to do something like this!" (Shropshire, Trust Director)

A school nurse who has worked closely with the Young Health Champions reported that it had made the service think differently. The service was re-envisioning the school nursing service and they have asked the Young Health Champions for their views on the school nurse role.

"I think the health champion project has allowed us to engage with young people in a different way, it's allowed us to [a] be creative and innovative and so think outside the box, think about what we could do and so that's where all this exploring of different mini projects has come from and it's been brilliant from that perspective." (Shropshire, school nurse)

At the Orthopaedic Hospital in Shropshire the Young Health Champions are helping them to get the young person's view into the service.

"They've asked us to take part in the 15 Step Challenge assessments of the children's ward and ...they've taken part in interviews for their new play specialist on the children's ward, so they've involved us quite a lot." (Shropshire project Lead)

The Young Health Champions involved in the Mission Impossible public transport project are presenting their report to various public bodies. The youth worker noted that as the young people are independent of the organisations they can be honest and change people's thinking.

"They're in the middle of writing a report and that report will then be presented by the young people to the people that matter, so we've got a Health & Wellbeing Board from the CCG, that are going to sit down and listen to them. We've also had interest from the council and other bodies that want to hear what they've got to say and because the young people are independent, they don't have the political ramifications of jobs and other things, they say it like it is and a lot of their personal experiences really hit home to professionals and it brings it back down to earth, "Why are we doing this and what are we doing it for?"." (Shropshire, youth worker)

The youth workers were also helping Young Health Champions create new activities in schools.

"I personally go in and meet the group after school and we use a space in school for them to discuss what they want to do in school and then I liaise with school staff and the young people liaise with school staff actually, help them write letters or work around conversations and stuff and then I suppose it's about getting clearance of what you can do in school and "Will this work?" (Shropshire, youth worker)

The project lead explained the impact the Young Health Champions were having on local organisations.

"I would say it's a small step change at this point, I would say that what's happened really notably locally, is that people have realised that young people's voices are not simply idealistic and they don't wish for the world, that actually they come up with some really good ideas and they are now, actively seeking them and not just in a "can we have a young person on this committee?", it's more like people are coming to us and saying, "We're doing a piece of work around CAMHS, we'd like some young people to help us, what do we need to do?", instead of, "We're having a meeting, can you bring some young people?", it's changed to "We're going to be doing this, what do we need to do, to do it well?"." (Shropshire, project lead)

The GP lead of the CCG saw the young health champion work as part of developing resilient communities and also altering the nature of voluntary work which traditionally has been done by older people with time to spare, creating additional social capital.

"So I think what we are probably seeing is the beginnings of a resilient community within young people but also probably the next generation of the voluntary sector but at a much younger age, which as to the sustainability of volunteering, is really

important but also I think we could be seeing the start of, where currently volunteering is something that you do towards the end of your career, where you've got additional capacity, it's now potentially being built into business as usual, so your day to day lives, they will keep doing this kind of voluntary work with the voluntary sector that they're involved with throughout their careers and life, so it's a completely different approach and I think that's how it's going to make communities sustainable because at the moment, as you know, we depend very much on that much older population to kind of prop things up and if we can get that social capital going from a young age, then we're in a different place." (Shropshire, GP lead)

The GP lead also related the young health champion work to the needs of the NHS in the future focusing on the population's need for social support.

"I think particularly at the national level, this is about we make NHS sustainable so it wasn't all kind of benevolent from our side, the reality is I can't afford to keep buying everything that the population locally needs and probably 20% of what they need is social support in their communities, this is where you build it, you actually teach people how to do that themselves and to give that back to their communities themselves, so this is a real investment in the future." (Shropshire, CCG GP lead)

Youth Workers' Perspective

The youth workers were very enthusiastic about the work they had undertaken with the Young Health Champions. It was very different to their usual youth work. Their comments included;

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"Given some meaning back to it."

"I've got a new purpose."

"It's what we were trained for!"

"This is youth work."

"Young people agendas. It's bloody marvellous!"
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"I'm back being a youth and community worker! Because instead of being – it sort of drifted off into being youth work and actually I was trained as a youth and community worker and this is about getting young people involved in the community, developing contacts with organisations, adults, different sets of the community and them being part of that."

Sustainability

The evidence in the section on 'System Change' demonstrates that sustainability is being built into local services. The CCG wants to make the work sustainable and aims to create 500 Young Health Champions in three years from the ending of the BIG Lottery funding. So far they have secured funding for the next 12 months. In the climate of public service cuts, it is difficult to plan further ahead.

"It's written into our budget, I'll be absolutely honest, because of all the national cuts, it's been much more difficult to get the additional funding out of absolutely everybody, however we have managed with three of the big stakeholders which is really impressive, so we've got the local authority, the police, we've got the fire service and obviously us and we'll work on it from there." (Shropshire, CCG GP lead)

PERSPECTIVES FROM THE ALTOGETHER BETTER TEAM

The health champion work had been prototyped originally working with a small number of enthusiastic practices in Leeds. In this programme they were rolling the health champion work out to a greater number of practices and over a large geographical area. The Altogether Better team have learned an enormous amount from the roll out and there are many aspects of the work they would have done differently with hindsight and they have incorporated these insights into new practices that have come on board with the health champion work.

"I know that there's a huge gap between the initial enthusiasts and it going wider and that's actually usually the most difficult thing to do, it's not usually difficult to invent something completely new that's fantastic, the difficulty is getting it more widespread." (Innovation Hub 1)

Also, the Altogether Better team acknowledged that they didn't fully appreciate how pressured GPs and practice staff were during the time of the project (and still are).

"I think maybe the other bit of learning is just how desperate a state general practice is in, never appreciated how absolutely horrendous state it's in." (Altogether Better, director)

There were initial starting conditions that Altogether Better did not have any control over such as (1) working mainly in areas where they had worked before in order to build on previous work (2) working through regional NHS bodies, and (3) project leads were appointed locally with no input from Altogether Better.

"Some of the learning, we'd never go into anything where we had so little influence over the project leads but that was a condition of the Big Lottery grant, money had to go to that, had to be locally appointed ones and if we had known the degree, we would have insisted we had a role in appointing them but we didn't know that at the time, so that's with hindsight." (Innovation Hub 2)

Targets

The Altogether Better team acknowledged that targets had a very distorting effect on the health champion work. Project leads were focused on the targets, timelines and training, and support for champions trying to start activities was further down their list.

"I definitely think the targets did a lot of damage, I don't know at what stage it turned into an excuse because I still don't believe you spend five days a week, these are full time jobs, do I think they spend five days a week chasing targets? Could they have spent one day a week supporting ...?" (Innovation Hub 2)

"I think the targets and the deadlines together were very destructive in some places." (Innovation Hub 1)

There was also a recognition that there was value in things other than numbers of champions, such as just a single champion making a difference in the practice.

"So a lot of my assumptions about you need to have a critical mass of people for it to make a difference, it helps for sure and we know that sometimes it's a struggle when there isn't enough but M (health champion) on her own, has found a niche, she comes in everyday ... So I think I've learned a lot about valuing what other people have shown me is worthwhile." (Altogether Better, director)

Practices

The Altogether Better team learned that practices needed time to develop the health champion work in a way that works for them. One practice, which had been on the verge of abandoning the work at the beginning, developed the health champion work in their own way to the point where they weren't going to let it go, even if there was no further funding.

"The meeting we had at the very beginning was a meeting in which the GP was actually planning to cancel the whole practice meeting the day before it happened and pull out of the whole programme, so it was a place that had an immensely rocky start. But going back 18 months later, we had three of the four doctors, the practice manager, several receptionists and especially the person who does the liaison with the champions and they were so enthusiastic....I think they've got there, they said "Whatever happens, this will continue in this practice, if there isn't external funding, this has got to continue", so they're completely convinced that this is the way they want to go, even though there are all sorts of things about it that don't fit the way that we normally do it." (Innovation Hub 1)

"So I think this whole thing about you have to hold your nerve and there'll always be failure in the middle, it does, because in the middle they're looking for results because that's how they see the world and it might not be as far as they want but if we can just stay with them long enough, they see it and when they see it, that's fabulous." (Altogether Better, director)

The Altogether Better team were shocked at the time gap between recruitment of champions and health champion activities getting off the ground. Although the health champion activities were originally envisaged as self-initiated groups, in retrospect, the team recognised that some early activities in the practices would keep the momentum of health champion enthusiasm going and start to create a relationship between the health champions and the practice.

"There'd be a whole range of stuff around start-up differently. I think again, we either missed or we had been lucky in our experience of project leads before (in the prototype) but there was that horrific gap between training and anything happening

and I think there's a whole range of things we could do around big fixes, I think we've also shifted into ...that it's all right for particularly some of the practice ideas to come forward earlier, as a way of getting things going, as well as other activities that connect into other things that are going on in the community ,to prevent duplications and the connecting and signposting." (Innovation Hub 2)

The Altogether Better team felt they should have been more prescriptive in what they expected from GPs, not in terms of time, but in terms of connecting with the health champions through saying 'thank you', giving time to them in practice meetings and suggesting the health champion activities to patients they felt would benefit.

"I think there's something around we should have been more demanding of the GPs around the practice, that actually every month we expect five minutes of the practice meeting agenda to be given to this, we expect the stuff of your behaviour personally towards them and saying "thank you"." (Innovation Hub 2)

"I think, when new groups start up that are health related, that they help seed it, that they the practice has to take some responsibility for getting the first six people to any group that gets set up and they could decide it's through GP or nurse referrals or receptionist but getting it in consciously because I think once groups get six or so, then they're likely to grow and expand." (Innovation Hub 2)

The Altogether Better team have been surprised at the negative reception health champions have had in some practices.

"So I started this excited but with some trepidation and my particular interest was on how the practices would respond. I think I should have been more worried about how the practices would treat the champions because some of them ended up really treating the champions pretty badly and I hadn't anticipated that." (Innovation Hub 1)

"I'll echo J completely, it's been devastating, how badly staff have behaved towards people and so we've learned things to do, to try to mitigate that happening again, so we would never ever invite champions into a practice until we'd met the whole of the practice and we would never be desperate for a practice, so we'd only want to work with enthusiastic practices." (Altogether Better, director)

There were Community of Practice meetings for health champions and practice staff as part of the programme but it was felt that holding a Community of Practice just for Practice Managers would have enhanced the work of changing the way General Practice works.

"In hindsight, what I would have loved to have done is had a community of practice just for Practice Managers, around how they could do the challenge of running the practice in the future, but this is just one element, it wouldn't have been a practice of how you use champions, ... I think we could have got their interest and helped them in a whole range of other ways but just never thought of it until the very end." (Innovation Hub 2)

Project Leads

The Altogether Better team were surprised and disappointed that the project lead job description was changed in some regions and they felt this impeded the health champion work.

"So we produced sample job descriptions but then people changed them and then the way they changed them meant that people were recruited not to do the jobs that needed to be done. So for example, the (region) team changed the job to be just a recruitment and engagement role and then 6-8 months in, they didn't know that they were meant to be supporting champions and you think how could you have been in these conversations and not known that?" (Altogether Better, director)

"(Trust director) appointed (project lead) who was a Band 6, so in terms of having clout, had very little clout and very little relationships, so a very hierarchical way of being. It failed from the beginning for me in that the workers had their own job descriptions, they thought they were only going to be working with champions, they didn't think they were going to be doing anything with the system." (Altogether Better, director)

There was also the feeling that the formal world of the NHS had a negative impact on the development of this new way of working in GP practices.

"I think what we learned from (Innovation Hub) with the discourse analysis and the two world views, people either hold a preference in one place or another and where it hasn't worked that well, has been where people really sit in the formal world, so I would say in the (region) it hasn't worked well because the formal world's pulled so hard and then places like, where the needs of the formal worlds are more important so in (town) to find out that after six months of training, they never had met with a champion, now that is hugely disappointing, how could you begin to think that that was okay?" (Altogether Better, director)

At the time of the evaluation interviews most of the health champions had only just realised, or hadn't realised at all, that the project team support was going to end shortly. This was a disappointment to the Altogether Better team who had assumed that the project teams would have told health champions when they would be stepping back.

"From Day 1, it's always been known it's only two years, from Day 1 we've been talking with people in the communities of practice, from Day 1 the model's been designed to embed it so the practice can run with it when we fall back. ...So that's a huge disappointment that somehow, somebody didn't hear, see, understand, so I think I've got from a disappointment point of view, is you think that people are on the same page as you, you think you've shared something but you haven't. And M says this thing about you have to say something three times for people to hear, I think you have to say things 33 times for people to hear." (Altogether Better, director)

In retrospect the Altogether Better team feel they should have run a training course for project leads at the beginning of the work and held a monthly project leads' meeting.

"That's the other thing, we would have done a one week training course for the project leads and that really would have been building a relationship with them, getting them not to think of us as performance managers... and I think if we'd done a one week induction type course or something like that... we could have built a good relationship that I think would have also changed, allowed us to all learn faster together." (Innovation Hub 2)

Whole System Events

The Whole System Events in the Shropshire and Barnsley projects were seen as very different with regard to the energy and attitude invested in the health champion work.

"One of the things that disappointed me about the very first meeting in Barnsley was that there were a few ideas that came up there, with enthusiasm, we talked about the limitations of the champions but there were some super champions there ...who came up with all sorts of interesting ideas like pregnancy buddies and things like that, that clearly the midwives and health visitors could see the value of but there didn't seem to be any sort of institutional willingness to take this up... so I wondered why they were all there." (Innovation Hub 1)

"In Shropshire there was so much, so that's the other thing about the learning, when you see things begin to happen, other things become more and more possible and it's like a ripple, it runs out and the examples in Shropshire, there are so many...And I think they were fabulous, the young people were full of 'can-do'." (Altogether Better, director)

Sustainability

The Altogether Better team have learned that there are many ways to sustainability of the health champion work. In some case the enthusiasm of the health champions will keep the work going even without a strong connection to the practice. Some of the health champion groups have made themselves into a charity so they can make bids for small amounts of funding. In other cases the practice will continue to support the health champion work and in some areas the CCGs have provided funding to further the work.

"In terms of sustainability, I think there are multiple routes, there's clearly champions who have got the energy and enthusiasm and will just continue it no matter what and get as much out of the practice and connection with the practice as they can. There are some practices, which clearly reckon that this is the way they want to go and will continue to support it with at least their own time and a bit of space and maybe even a bit of money. Then there some places in which the CCG is prepared to give it a go for another year or two years or whatever it might be, so there are

different sorts of levels and when you look at the champion based ones, then some of those are doing fundraising, setting themselves up as charities, doing all those sorts of things which it's a shame that they have to waste their time doing all of that in a way, but given that there ought to be sources of funding from the NHS but that's a possible way forward." (Innovation Hub 1)

Theory of change

The theory of change in the health champion work has developed during the course of the work, from observations and the early results of the evaluation. The theory encompasses the concept of citizens both changing or enhancing services, and realising that they can do things to help themselves and others. The theory also acknowledges that interacting with, and being valued by, others is central to the benefits of being a health champion.

"I think the theory is that you can use citizens as a catalyst to get organisations delivering services to evolve, as well as there's some evidence we can start to see... the potential for the community to learn, to see a different role in how they use services and things they could do for themselves well." (Innovation Hub 2)

"Being noticed for who you are and being connected to people that you can share experiences meaningfully and it might be people with a similar background or just people of similar isolation, is the profound human interaction that gives life to it." (Innovation Hub 2)

A NEW MODEL

Out of the rich experience of the health champion work and the recommendations of the Marmot Review, the Altogether Better team have developed a new model for the health champion work. This starts with the selection of practices.

"What the Marmot Review said is in order to lift people at the bottom, you need to work across the gradient, so in lots of the CCGs you go to, they're still in that place of "we must reduce health inequalities so we've got to start in the worst areas, with the single handed practices who have the most chaotic .. they have smaller staff teams", it's actually the worst places and the research says not to, it says work across the gradient and up and if you work there, you pull the whole up and that's what I think, where we've seen it work well, it works really, really well but I think it's actually wrong to start only with those practices who are the most needy." (Altogether Better, director)

The new model recognises the need to select practices which are enthusiastic about the health champion work and doing more pre-work with the practices and emphasising the important role of the receptionists.

"We've gone slowly, we've managed it ourselves so we haven't had to do it through another party. We took a while picking the practices, so the practices who are signed up, some of them we met with three times, on three different occasions... before we even went in on a practice visit. Then we go on a practice visit so we go and meet with them. We insisted that it needs to be for everybody, especially the receptionist because we've learned how important the receptionists are to this and we say to the receptionists when we're in the room, "You are critical to the success of this work and if you don't like this, if you haven't got time for this, if you think it's not for you, if it doesn't look like it's going to help you to do your job, then it might not work and it might not be for you"." (Altogether Better, director)

There are also now agreed dates for the whole practice meetings and commitments from staff to attend the training and a defined period of 6 weeks for recruitment of health champions.

"I think we've got a really clear and tight schedule of what happens when, so we wouldn't start before we've got a whole practice meeting date in the diary, so first time round, the project leads didn't set up some of the whole practice meetings for six months, it's absolutely bonkers and didn't feel like they had the authority, staff didn't answer their emails, it was really difficult, so now when we say to sign up, "You need to have your date for your whole practice meeting, you need to be able to come to the trainings as a welcome in the morning, to be there in the second afternoon", we have a room sorted, we have training sorted, we have a six weeks run-in of recruitment so that we've got six weeks in each area beforehand."

The Altogether Better team provide the wording for the text that practices use for recruiting people as health champions and they now focus on larger practices. Additionally they recommend that practices recruit people from the local community, not just people from their patient list.

"We also say to the practices upfront, "This is not about your patients, this is about inviting people on your list but it's inviting people in the community" because otherwise they're so very limited and also we get away from this notion of patient champion, which feels like the practice own ... So we talk about it being wider than the list and try and encourage that where we can because we learned that caused us problems." (Altogether Better, director)

There are now no targets for numbers of health champions in the new practices. The emphasis is now of quality not quantity, in terms of recruiting people who fully understand the work and are committed to it. This approach has not reduced the number of health champions. Recruiting the larger practices to take part in the work also ensures there is a reasonably sized patient population to recruit from.

"We're saying it's around quality and effectiveness but what you do is you make it visible and then it hopefully encourages and builds numbers, so we're getting pretty good numbers in Wakefield but we are going for larger practices as well, so we're not going for practices of 1500 or something like that." (Innovation Hub 2)

The Altogether Better team feel that the training does not need to change because it evaluated well. They ensure, however, that training is provided by the Altogether Better team after difficulties with a previous provider.

The team have also learned from early evaluation data that health champions enjoy working with people of different ages and from backgrounds and cultures that they wouldn't ordinarily meet in their everyday life. The team now bear that in mind when recruiting practices to take part in the health champion work.

"I think we now also know we need to work with diverse populations or it's better when you do and if you just work with, so if you work in a totally South Asian population, it's as bad as working in middle class (town), where they're all white and older people, it doesn't work equally well or it's harder work when the people are all the same and what we've learned from the data is that the thing that the champions value most, is meeting people who are different from them, so we have to do that on their behalf, so we have to pay attention to that." (Altogether Better, director)

The team have also observed that it's important to recruit and nurture a stable group of champions before including others who are poorly or who have mental health problems.

"They got a really solid mixed group of champions and then they started to recruit people who had severe mental health problems, who have benefited massively but you could never start there. But in some of the practices, the needs, they were all the same, a lot of them were old, South Asian women who were poorly and didn't have a

gift to give, so I think there's lots we've learned about who to recruit and recruiting for diversity but also being pretty solid to start with." (Altogether Better, director)

The health champions in some areas had spontaneously started to join together both in terms of activities, such as Walking Groups, and in 'review groups' across practices to exchange ideas and support each other. This development has been brought into the new health champion work.

"What we're learning from the work with champions is they're teaching us about federation because they're coming together in hubs and they're not worried whether or not they do this for this practice or this practice. If they're running a walking group, they might open it up to three local practices, the practices are really cautious about doing things together because of their business interests but we're seeing champions model it." (Altogether Better, director)

DISCUSSION

Summary and Discussion

Whilst there have been many successes in the health champion work it has been more challenging than the Altogether Better team expected, based on their experience of the successful prototyping in Leeds. One of the crucial differences between the early prototyping and Wellbeing 2 has been in developing a new relational approach with a broad range of subcontracted local delivery partners. Partners found themselves working against challenging milestones and targets because of long delays in the appointment of Project Leads and engagement staff. Some local teams working under pressure had difficulties in finding and engaging Champions and work within practices was consequently slower than expected to get off the ground. The emphasis on achieving Big Lottery Fund engagement targets, however, meant that project teams did not give as much support as practice staff and health champions felt they needed. Furthermore, the concept of developing the work themselves, in conversation with practices, was a surprise and a challenge for many health champions. Many were expecting a more traditional volunteering role and wanted the practice to tell them how they could help.

Initially, the concept of the work was unclear to many of the health champions and often to the practice staff. This lack of understanding was one of the contributing factors to the slow start of the health champion activities. In some ways this is not surprising as it is innovative and most people have been brought up in a culture where they have been told what to do and where conforming to expectations in schools and employment has been valued.

The work has demonstrated that becoming a champion can be life changing for some people and life enhancing for many others. The changes were due to feeling more confident, having a purpose in life, giving back to something they believe in and making good friends. In some cases champions were feeling physically better. These changes were often achieved even where the champion activities were not especially successful, suggesting that the process of being in a relationship with others is as important as what happens. Champions also said they enjoyed getting to know people from different backgrounds and cultures that they would not normally get to meet in their day to day life. The health champion work, therefore, has the potential to contribute to community cohesion. In the young health champion work young people enjoyed meeting others from different backgrounds and different ages. The Altogether Better Team have integrated this finding and, in the case of GP practices, aim to recruit a diverse group of champions, both cognitively and culturally, to create the richest environment in which relationships, and the work, can develop.

All of the Practice Managers felt that the health champion work created more work for them than they had expected. They believed that the health champion work, supported by the project team, would not need much input from the practice manager. In reality there were communication and organisation issues, plus time spent easing relationships between staff and health champions where there were tensions around health champions using practice space. On top of the current pressures in GP practices this was frustrating for many Practice Managers. The practices which had on-site project workers were more successful in establishing health champion activities.

Some Practice Managers and many GPs and receptionists were often unclear about who the health champions were and what health champion activities were available. Even when they did know about the activities they were often not up to date with latest developments. This was due to the lack of established feedback mechanisms for the health champion work. Practice staff had many different ideas on how this could be achieved in their practice. If GPs and receptionists are fully informed about the activities they will have the confidence to suggest activities to people they think may benefit. Receptionists potentially have a key role in the health champion work being on the frontline of the practice and having considerable knowledge of the patient population. They also have a key role in making the health champions feel welcome and part of the practice.

In the new model of health champion work all of these challenges have been addressed by doing more 'pre work' with practices explaining the work involved and selecting only those which are enthusiastic about the work and willing to support and value Champions and the work they do. The practices are encouraged to establish explicit feedback mechanisms and the role of the receptionist in the health champion work is emphasised as key in recommending health champion activities to patients and making champions feel welcome in the practice. The practices are encouraged to have photos of the champions in the waiting area to help the staff recognise champions and to demonstrate that they are part of the practice family.

An important aspect of developing the health champion work in practices is the visibility of the champions. This advertises both the role of the health champions for anyone who may want to join them and the activities they have created. It also familiarises the practice staff with their presence. The project leads discovered that having a handful of ideas ready to work on — for example health awareness days, helping with one-off events, helping navigate patients around the practice - was a good way of quickly establishing the health champion work. It (a) familiarised the staff and the health champions with each other, (b) it made the health champions feel useful and kept up their momentum for the work, (c) it made the health champions and their work visible to patients and practice staff (d) the practice benefitted immediately from the health champions' contribution, (e) it satisfied those champions who wanted to help the practice directly rather than set up groups, (f) it allowed time for health champions to gain confidence in the work. The new model for

practice based work now encourages this early work in the practice as a way to create something tangible to build on.

Good relationships between practice staff and health champions are essential for the success of the work. There were some instances where the health champions were not treated well by the practice staff. For the work to be successful the staff, especially GPs, need to be made aware that even seemingly simple acts such as 'hello' and a 'thank you' go a long way towards making health champions feel valued. The perceptions of the relationships can differ between the health champions and practice staff where staff do feel appreciative of the work but health champions are not aware of this appreciation. This is an area that requires some attention through regular dialogue.

There are also tensions with practice staff with regard to the presence of the health champions in their kitchens and rest areas. Relationship building is key to easing these tensions, as is ensuring before the work starts that the practice is willing to welcome Champions into the practice in the same way as a new colleague. Increasing the staff knowledge of the work and giving people time to get to know each other are essential for building good relationships. The benefits of good relationships are that people find it easier to contact each other and resolve issues, and they are more forgiving of each other when mistakes are made. In these conditions the work is more likely to flourish. Practice staff attending the welcome workshops for new champions can help to create good relationships and ensure the staff have a thorough understanding of what the champions are doing. Although, Altogether Better have asked project leads to encourage staff to come along at the start of the welcome workshops to welcome champions, they have also offered staff the opportunity to be part of the whole workshop.

Relationships within the health champion groups are generally very good but there are occasionally difficulties where there is a challenging personality. Project leads struggle to resolve these situations and there is some evidence that champions leave because of these personalities. It may be that the improved recruitment methods will reduce the incidence of these difficulties but project leads also need help to resolve them.

Champion activities, especially the groups, are dynamic in that they are always work in progress. Groups may not initially attract many participants but changes of focus or venue or timing, or joining with another practice or another community group, can make it successful. Sometimes, simply waiting for numbers to build as people get to hear about them is necessary. It's vital, therefore, that champions, practice staff recognise this dynamic and see it as the road to success rather than letting disappointments demoralise them.

There were some instances where practices were unhappy with the activities suggested by the health champions. Whilst practices have to be comfortable with the health champions' activities they also need to understand the demoralising effect for health champions of having an idea rejected. Good relationships between the practice staff and health

champions would help increase understanding in these circumstances and, hopefully, not diminish the health champion's enthusiasm for the work.

A key aim of the work has been to change health services by bringing a diverse group of people into the practice who can offer different solutions. This might include providing more social activities to meet the non-clinical needs of patients thereby reducing pressure on health services, and by integrating citizens into health service systems so they can shape and change the development of health services. The work had not been going long enough to exert such 'system change'. The slow recruitment of project leads, the slow start to creating activities due to the focus on recruitment and targets meant the work was in the early stages of making an impact on health services. There was some anecdotal evidence that becoming a health champion or participating in health champion activities reduces visits to GPs, which indicates the potential of the work to create system change (as in Robin Lane). In the Young Health Champions work, young people are included in the decision making process of the Clinical Commissioning Group (CCG) and not just on issues related to young people's health. The staff of the CCG felt it gave their decision making a new dimension and made them 'think differently'. There were three factors crucial to the success of this approach; firstly, the investment in the time of the CCG staff which enabled the inclusion of young people; secondly, the training of the young people in the knowledge and the confidence to make a meaningful contribution; thirdly the existence of a permanent group of young people of different backgrounds that the CCG could call on to be involved rather than having to gather a group of young people just for consultation. Partners in the Whole System Events also found that the young people made them 'think differently'. Their contribution changed the nature of the efforts of the police and fire service to increase community safety.

In the GP practices participating in the Big Lottery programme, there is as yet little evidence that health champions were becoming part of the decision making processes, but evidence from other work is demonstrating that this is beginning to happen. At specialist service, however, the health champions had been asked to contribute their views on the development of the clinic from the very beginning of the health champion work.

One indicator of system change is providing physical space within the practice for champion activities. Some practices talked of creating space for health champions within the practice which demonstrated a move towards including the health champion work as part of the practice on a permanent basis. Given the practical reasons for providing the health champions with space and the symbolic message this provides, the new model for health champion work encourages practices to find space for health champions within the practice at the very beginning. Creating space in the practice at the beginning of the work will also contribute to the sustainability of the health champion work.

Sustainability of the work took many forms from CCG and Trust funding to health champion groups applying for charitable status so they could raise funds, to needing no money at all.

It was clear that some health champions were only aware of the end of funding and project worker support very close to the end of the project. The Altogether Better team were disappointed that this message did not seem to have got through to some of the champions

The health champion work has been very successful in the Young Health Champions project in Shropshire. The work benefitted from the enthusiastic support from the CCG, a project lead known to them, and a team of youth workers commissioned by the project lead to support the Young Health Champions. The project lead also invited stakeholders to take part in the 'train the trainers' programme so that they would have a detailed understanding of the programme and thereby increase their support for the work. The project lead felt that the commissioning of the youth workers and the training of stakeholders had been critical to the success of the work. The Young Health Champions with a great deal of energy, a 'can do' attitude and the support of the project lead and the youth workers initiated many successful projects. The young people enjoyed the responsibility of the work they were undertaking and the friendship groups they formed provided support for each other in life's difficulties. The CCG have secured funding for the work for the next year and hope to find funding for another 2 years. They aim to recruit 100 champions per year

The health champion work designed to give children in Barnsley a Better Start focussed on finding and training Pregnancy and Early Years Champions. The project reached the target recruitment figures largely by recruiting college students to the course, but was less successful in developing relationships with the champions and any health champion activities. Some groups were starting towards the end of the project funding. The team had intended to recruit from the Children's Centres but this had been unsuccessful and they did not link in to relevant health services such as maternity and health visitors. The team driven by the desire to reach targets then recruited randomly from the town and a local college which meant that champions had no base and some had no interest in pregnancy and early years. Added to this the team were late into post and the focus on recruitment meant that health champions were not sufficiently supported. There are now some strong activities starting but there is no evidence of a firm base to keep them sustainable. The discussion at the Whole System Events were enjoyed by stakeholders but there seemed to be little connection to the work that health champions were trying to do and the ideas that came out of the discussion were considered by some stakeholders as not achievable in the current political and financial climate. The project lead is funded by the Trust to provide some part time support for the health champion groups until March 2016 but there will be no further recruitment or training.

In summary the health champion work requires enthusiasm and commitment from practices and senior levels of the local health services, more support for health champions to help them develop their activities and the creation of good relationships that will allow the work to flourish.

A new model for health champion work has been developed based on the observations and learning of the Altogether Better team and the learning from the evaluation process and early indications from the application of the new model in other areas are very positive.

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