

Community Researchers and the Big Health & Care Conversation

January 2018
Report

Connecting charities, volunteers and businesses



Contents

Community Researchers and the Big Health and Care Conversation	3
Background and Methodology.....	4
1. What we learnt: Making it easier to see your GP	6
2. What we learnt: Helping you stay healthy	9
3. What we learnt: Making better use of medicines	11
4. What we learnt: Improving referrals from GP	13
5. What we learnt: Preventing you ending up in A&E	15
6. What we learnt: Keeping you out of hospital.....	17
7. What we learnt: Treating Mental Health Equally	18
8. What we learnt: Giving Children and Families a Better Start	20
9. What we learnt: Sustainability and Transformation Partnership.....	21
Appendices	22

Community Researchers and the Big Health and Care Conversation

This Community Researcher Project is part of the Brighton and Hove Clinical Commissioning Group's (B&H CCG) Big Health and Care Conversation initiative which ran from July to December 2017. The Big Health and Care Conversation built on previous feedback from patients, carers and the public and gathered views from people across the city on local health and care services in order to help shape the way they are designed and delivered.

This Community Researcher Project worked with previously trained community researchers from communities who may not otherwise be heard. Five organisations worked in partnership to reach a total of **83 people from different communities**. This was well above the original target of 32-48 people.

Recurring themes

1. Making it easier to see your GP

- Improved booking appointment systems are needed.
- More GP appointments available as drop-ins, or at weekends and evenings.
- Longer appointments that could explore more than one issue.

2. Helping you stay healthy

- More information about local activities and community groups.
- More information, education and support for healthy life styles.

3. Making better use of medicines

- More publicity about how to get information about medication.
- Promote and enable wider use of pharmacists.

4. Improving referrals from GP

- Earlier referrals for tests and scans that is actioned.
- Shorter waiting times for referrals.
- Services delivered locally and more information about community services.
- Improved appointment systems, better communication between GP practices & hospitals.

5. Preventing you ending up in A&E

- Timely cancer diagnosis would impact on emergency admissions.
- More coordination between services would reduce A&E visits.
- More information about alternatives to A&E is needed.

6. Keeping you out of hospital

- Improved communication and connections between health and social care services is needed to help keep people out of hospital.

7. Treating mental health equally

- Increased provision of mental health services is needed in a timely and accessible way.

8. Giving children and families a better start

- Improve the relationships between young people and social workers.
- More information about childhood vaccinations would help increase uptake.

Background and Methodology

Each partner engaged people through face-to-face interviews, surveys, or a focus group around the Caring Together conversation themes. The focus groups were co-facilitated by peer community researchers and/or staff.

- **Age UK Brighton and Hove (Age UK B&H)** engaged with 22 older people and consulted with eight people who have experience of cancer.
- **Community Works (CW)** worked with a Patient Participation Group (PPG) member to reach four patients.
- **Hangleton and Knoll Project (HKP)** worked with Youth Health Champions to reach eight young people.
- **Sussex Interpreting Services (SIS)** worked with migrants based on their migrant needs assessment role. They reached 21 people.
- **The Trust for Developing Communities (TDC)** worked with people from economically deprived communities to reach 20 people.

Of the 83 people interviewed 26 were men and 57 were women. Three said they were from the LGBT community and 21 said they were from the Black, Asian and Minority Ethnic (BAME). 56 people said they were over 50 and nine said they were under 26. Seven people said they were disabled, twelve people said they were carers and 25 said they were parents. Finally, eight expressed a faith.

The partnership has unique skills and experience in reaching communities across the City. Over many years we have each built trusted relationships with communities and can engage them in conversations about health and care that other services wouldn't be able to do.

Community Works is experienced in coordinating a range of health related partnerships, providing facilitative spaces and events that, through partnership working engage a diverse range of groups and individuals. They bring social value to a consultation of this kind through its membership, network and growing track record on community research, providing quality, community-based and values-driven consultation.

Trust for Developing Communities improves lives through community development work in Brighton and Hove. They identify individuals and communities facing challenges, then set up and support community groups that tackle these specific needs and problems. They help groups with training, funding applications, governance and accessing services, so that people in our communities are empowered to take control of their own lives.

Hangleton and Knoll Project works in partnerships with residents to access and develop opportunities and resources and to facilitate positive change. Their broad aims are to assist and support new and existing community groups, facilitate external services wishing to provide services, promote and support the development of community buildings, parks and open spaces and to encourage the participation of local residents in all forms of voluntary activity, education and employment.

Age UK Brighton and Hove's main concern is the welfare and needs of older people in the City of Brighton and Hove. They offer a wide range of services for older people including advocacy, nail-cutting, a crisis service and information and advice.

Sussex Interpreting Services is an independent social enterprise and charitable company working to relieve the poverty of individuals from BAME communities by providing community interpreting and translation, communication services, confidential advice, assistance and information.

Table 1. Demographic Details of People Interviewed

	Older people	People with experience of Cancer	Patients contacted through PPG members	Young people	Migrants	People from economically deprived communities	TOTAL
	AGE UK B&H	AGE UK B&H	CW	HKP	SIS	TDC	
Men:	6	3	1	6	4	6	26
Women:	16	5	3	2	17	14	57
LGBT people:					2	1	3
BAME people:					20	1	21
People over 50 years:	22	8	3		10	13	56
People under 26 years:				8		1	9
Disabled people:	2				1	4	7
People who are carers:	4		1		4	3	12
Parents:	5		1		13	6	25
People expressing a faith:	2				5	1	8
TOTAL	22	8	4	8	21	20	83

1. What we learnt: Making it easier to see your GP

44 people responded

Issues Raised

1.1 This older couple find it very **difficult to see their GP**; they would prefer not to queue outside the surgery at 8:00am without seats to get an appointment. (Age UK B&H, Older People 1)

1.2 This woman would like to **make GP appointments for the next day**, she has rung for an emergency appointment, but none were available. (Age UK B&H, Older People 2)

1.3 This woman would like it to be easier to make urgent appointments otherwise she goes to A&E. (Age UK B&H, Older People 4)

1.4 This man finds **contacting a specialist pituitary nurse difficult**. (Age UK B&H, Older People 6)

1.5 All three of these women found **making a GP appointment difficult**. One had found a **drop-in centre in Shoreham very good** and would like to see more in Brighton. They would all like **help with transport to get to appointments**. (Age UK B&H, Older People 7)

1.6 M would like a way of having **quick word with her GP rather than a formal appointment**, perhaps a service for people with long term chronic conditions? (Age UK B&H, Older People 8)

1.7 N would like **more continuity** by being able to see the same GP. (Age UK B&H, Older People 9)

1.8 S has **difficulties seeing his GP**, either he has to book online or phone at 8.00am, but he can never get through and by 8.15am all the appointments are gone. He would like to see a **triage system used in surgeries**. (Age UK B&H, Older People 10)

1.9 This woman is very happy with her GP, but she is extremely anxious that the **surgery might close**. (Age UK B&H, Older People 11)

1.10 The person **did not get a call or home visit by a GP when expected**. She went to A&E instead as the only way to get treatment. (Age UK B&H, Older People 12)

1.11 This woman has **problems making an appointment**, she tries early in the morning if urgent but sometimes can't get through at 8:00am - or 3:00pm when the other slot opens. (Age UK B&H, Older People 14)

"Getting to see my GP is very difficult, my partner was ill recently, had to stand out in cold from 8am for 30mins. I have rheumatic arthritis myself." **Age UK B&H Older People 1 Interviewee**

"Being able to make appointments for next day. In my job I can't just take time off work to go." **Age UK B&H Older People 2 Interviewee**

1.12 This man is frustrated with: **getting an appointment**, hostile receptionists, the triage system of calling people back at home, three week waits for an appointment, not understanding the home visiting criteria. He has never used NHS 111 and would prefer to go to A&E to prevent a delay. (Age UK B&H, Older People 14)

1.13 This man would like the **effectiveness of telephone consultations** reviewed, **more information about out of hours services**, **clarity about home visit offer** and whether the **one symptom per appointment** is appropriate especially for older people with complex needs. (Age UK B&H, Older People 17)

1.14 S praised her GP surgery highly. She is impressed that she was telephoned on a Friday evening having only had the blood test earlier that afternoon. She can get appointments on the same day. (Age UK B&H, Older People 19)

1.15 This woman knows her GP well and **can get an appointment or home visit if necessary**. She has to walk to her surgery as there is nowhere to park. (CW, PPG 1)

1.16 This mother can get appointments with her GP for her two-year-old daughter. (CW, PPG 3)

1.17 This woman has **difficulty getting appointments**, phones are slow to be answered and then there are no appointments. Queuing outside before surgery isn't ideal. Better online booking systems would improve things. (CW, PPG 3)

1.18 This couple would like **more drop-in options to see a GP, children prioritised** rather than queueing and **weekend and evening appointments**. More GPs would help with this. (SIS 1 – Bengali Speakers)

1.19 This woman thinks that the **appointment system works well** and is much better than a drop in. Could the out of hours GP also make appointments? (SIS 3 English speaking Polish migrant)

1.20 This woman is generally satisfied with her surgery but finds **making urgent appointments difficult**. This is **compounded by the need to book an interpreter**. Double appointments would help explore more complex issues too. (SIS, 7 Farsi 3)

1.21 This woman has **problems with making appointments** as she needs to queue at the practice. More health care professionals would help as well as weekend and evening appointments. (SIS, 9 Polish 1)

1.22 This person has **difficulties making appointments** with long waiting times and no weekend or evening appointments. (SIS, 12 Polish 4)

1.23 These three women felt that a **two week wait for an appointment was too long** and they would like to have **longer appointments**. (SIS, 13 Portuguese 1)

"This conversation was very positive. S could not have praised her GP surgery highly enough. She was particularly impressed that she was telephoned at home on a Friday evening having only had the blood test earlier that afternoon. S is in her 80's." Age UK B&H Older People 9 Researcher

"Nowhere to park, have to walk there-not nice if you're ill." PPG Interviewee

1.24 This woman would like an **online booking system available for all GP and nurse appointments** and improve organisation and administration in GP surgeries to avoid errors. (SIS, 13 Portuguese 2)

1.25 These three people would like more **information and education, so people know how to use services effectively**. Leaflets aren't as good as direct contact/information with service providers (doctor, pharmacist). This would affect the GP appointments needed. (SIS, 18 Spanish)

"You end up losing confidence because you don't feel welcomed at your local surgery to talk to anyone. This leads to depression." **TDC 1 Interviewee**

1.26 These eleven people have found it **difficult to book appointments** especially to get test results, they **don't feel welcomed at their surgery** because it is so hard to get an appointment, one **symptom per appointment doesn't help** this. They would like **more local drop in GP appointments**, more **GPs locally**, **visits from specialist** doctors/consultants on specific areas and to **build relationships with GPs** (TDC 1)

Recurring themes

- Improved booking appointment systems are needed
- More GP appointments available as drop-ins, or at weekends and evenings
- Longer appointments that could explore more than one issue

2. What we learnt: Helping you stay healthy

30 people responded

Issues Raised

2.1 Y said that when she first became ill she had **more support** – counselling and hypnotherapy from the Cancer Centre – and that these had really helped. (Age UK B&H, Cancer 1)

2.2 This man always **brings a companion to appointments** as the experience is overwhelming. (Age UK B&H, Cancer 2)

2.3 This woman is **well informed about diet, exercise, life styles** etc. and is convinced that it was her general good health that got her through her cancer treatment. (Age UK B&H, Cancer 3)

"Interviewee would benefit from a GP with a special interest in cancer – not necessarily her own GP but someone she could talk to." **Age UK B&H Cancer 6 Researcher**

2.4 This woman would have liked a **support group with peers/buddy** and access to a **GP with a special interest in cancer to talk to**. She thinks that the **expense of cancer** should not be underestimated: rapid weight loss necessitated new clothing/bras, private therapies, could **swimming or exercise be socially prescribed?** (Age UK B&H, Cancer 6)

2.5 None of the three participants had access to the internet, and felt strongly about being **excluded from online information**. They would like a **community notice board in each surgery, perhaps with different health themes** such as dementia and cancer. This would be easier than lots of leaflets. (Age UK B&H, Older People 7)

2.6 N found that **C-Side, the colon cancer self-help group**, was a big part of her wellbeing strategy after her treatment. She also praised the **Macmillan Horizon Centre** for the support she found there. (Age UK B&H, Older People 9)

"N told me that C-Side, the colon cancer self-help group, was a big part of her wellbeing strategy after her treatment. It was the only place that she felt able to talk freely about sensitive topics (e.g. her colostomy) and learn from other people's experiences." **Age UK B&H, Older People Researcher 9**

2.7 This woman enjoys time at the **Bridge Project and has learnt ways to stay healthy**, i.e. a diet and exercise (Age UK B&H, Older People 9)

2.8 This woman regards herself as **fit for her age**, and has a **good network of friends**. (Age UK B&H, Older People 13)

2.9 This person recognises the importance of **staying fit, a good diet and lifestyle choices**. (Age UK B&H, Older People 14)

2.10 This woman would like **self management to be the norm**. She would like more health **care professionals in Community Centres** (social setting), to have **information on the table in GP surgeries** not on the walls and **not to waste money on campaigns**. (Age UK B&H, Older People 16)

2.11 This woman would like to **prioritise preventative care**. If there was more holistic care and an emphasis on health not disease everyone would benefit. (Age UK B&H, Older People 16)

2.12 This man would like **loneliness among BME communities** to be a health and wellbeing priority. The NHS and the Council need to **encourage BME communities to be active socially** by offering free activities and public transport to bring people together. (SIS, 6 Farsi 2)

2.13 This woman would like **more support to keep well especially my mental health**. Her GP helpfully suggested a **life-style change through a website address and book**. She would like more support to make the changes. (SIS, 8 Hungarian 2)

"Unfortunately the majority of immigrants are feeling alone and isolated. Experience of loneliness and lack of exercise can lead to high blood pressure, smoking, respiratory illness, psychological distress, anxiety-depression and other disease. Consequently, physical inactivity places a significant economic burden on the NHS." SIS, 6 Farsi 2 Farsi

2.14 This woman would like to see **more resources used to prevent diseases and for educating people to stay safe and healthy**. **More information could be available about community resources**. (SIS 10, Polish 2)

2.15 This group of three would like more **information about healthy eating, more spaces to exercise, especially for the elderly and safer cycling** in the city. (SIS 17, Spanish)

2.16 This group of eleven would like more **local information about healthy activities and about cheap healthy quick meals**. (TDC 1)

Recurring themes

- More information about local activities and community groups
- More information, education and support for healthy life styles

3. What we learnt: Making better use of medicines

25 people responded

Issues Raised

3.1 Y would like to **see unopened unused medicine re-issued to other patients**, to avoid the waste and save the expense to the NHS. She has received lots of unwanted medication for her misdiagnosed gallstone from A&E. (Age UK B&H, Cancer 1)

"Y would like to see unopened unused medicine re-issued to other patients, to avoid the waste and save the expense to the NHS." **Age UK B&H Cancer 1 Researcher**

3.2 S was **prescribed a lot of surplus medicine and yet was unable to return** this. The oncologist only responded to a request from her GP to explain the various medications and possible side effects, so she could make a decision on which one to take. (Age UK B&H, Cancer 6)

3.3 This woman thinks **services should be more joined up** e.g. prescriptions – there ought to be **cross checking of contra indications by GP or Pharmacist** (Age UK B&H, Older People 18)

3.4 This man likes that his **medication doses are changed promptly** if tests show an issue. (CW, PPG 2)

3.5 This woman would like her **medicines and prescriptions reviewed regularly**, currently she gets an automatic prescription renewal for SRI mental health medication. (SIS, 2 English speaking German migrant)

3.6 This parent would like more time spent **looking holistically so that medication can be minimised**, and ways of treating/preventing conditions can implemented by families. She would like **a less medicalised approach to health** and ill health. (SIS, 3 English speaking Polish migrant)

3.7 This woman would like **pharmacists to make decisions and offer advice about medications**. If people **paid a nominal amount for medication there would be less waste**. (SIS 10 – Polish 2)

"There is a culture of treating symptoms rather than looking for the causes of difficulties. Currently one of my children has been having breathing difficulties and a recurring cough. The GP isn't interested in looking at what might be causing this, but has prescribed asthma treatment in the form of an inhaler to treat the symptoms if and when they arise although there have been no tests to confirm she has asthma or to look at what might be causing the cough. We also weren't fully informed about alternative or complementary treatments for asthma to use instead of or alongside the prescribed medication." **SIS, 3 English speaking Polish migrant**

3.8 **More information about how to not waste medicines** would be helpful, perhaps in GP practices, medicine bags or via pharmacists. (SIS, 11 Polish 3)

3.9 This group of three thought there should be **more information given about how to dispose of unused medicines**, perhaps through posters on buses or by pharmacists. They think **doctors often prescribe too many medicines and there is a lot of wastage**. (SIS, 13 Portuguese 1)

"They didn't know that they should return unused medicines to the pharmacist. One of the ladies disposes of old medicine in the toilet which the other ladies said would have a negative effect on the sewage system." SIS, 13 Portuguese 1 Researcher

3.10 This group of three thought that people need **more information about medication**. Many people don't know about pharmacists, or understand why their medicine is specific to them. They would like **GPs to explain more about medicines and for information to be available at pharmacies** as well as general publicity. (SIS, 15 Spanish 1)

3.11 This group of 11 were aware that pharmacists could help with information about health and medicines. They **would like pharmacists to be able to prescribe medication** too. They would also like **private consultation spaces at pharmacists**. (TDC 1)

"Yes, we are aware that you can use the pharmacist to find out more information about health and medicines without needing to see a doctor. But they can't always help you with prescribing." TDC 1 Interviewees

Recurring themes

- More publicity about how to get information about medication
- Promote and enable wider use of pharmacists

4. What we learnt: Improving referrals from GP

32 people responded

Issues Raised

4.1 This patient would like **GPs to make referrals sooner** and there to be **shorter waiting times** as the wait for her possible cancer scan was five months. (Age UK B&H, Cancer 3)

4.2 This woman would like **any referral (especially when the diagnosis might be a form of cancer) to be actioned as promised by the doctor**. (Age UK B&H, Cancer 4)

4.3 These three terminally ill patients think that their MRI **scans were too late along with the waiting time of a few weeks to see a consultant**. One client also felt they had initially been misdiagnosed by the GP (Age UK B&H, Cancer 5)

"The over-riding concern for two of the three people I spoke to was that of having received a late diagnosis. In the case of one client it was not until they had gone to a private hospital did they receive the diagnosis of their condition. The other client was clearly left very angry by having received a terminal prognosis six months after first seeing his GP." **Age UK B&H Cancer 5 Researcher**

4.4 This woman **waited a year to see a consultant** after her GP referred her for rheumatism. She would like there to be shorter waiting times. (Age UK B&H, Older People 4)

4.5 M would like to see all **departments acknowledge referrals** so patients they know it is being processed. M would also prefer to see **better triage in the community** such as specialists working from local health centres. (Age UK B&H, Older People 4)

4.6 This person **could not get to see a GP for a referral** so went by ambulance to A&E as the only way to get treatment. (Age UK B&H, Older People 12)

4.7 This woman would like **better communication about systems and processes** so that one is not left confused or unsure about how treatment will progress. (Age UK B&H, Older People 13)

4.8 This mother finds it **difficult to get a referral to hospital maternity services** so she now goes there directly. (CW, PPG 3)

4.9 This mother thinks that GPs try to reduce unnecessary referrals by **waiting until symptoms are really severe**. She would like NHS staff to be able to make judgements about whether a referral is necessary; **earlier intervention by a specialist practitioner** could resolve issues sooner. (SIS, 3 English speaking Polish migrant)

4.10 This woman **goes directly to A&E rather than wait for a referral**. She would like referrals to be quicker to prevent further health issues. (SIS, 5 Farsi 1)

4.11 This woman would like **shorter waiting time for GP and interpreter appointments** in order to get a referral. If someone has a special condition in A&E, she would like them to **see the specialist team immediately**. (SIS, 7 Hungarian 1)

4.12 This mother needed to **see her GP several times to get the right referral** for her child. This led to a longer recovery time. She would like **quicker referral times** as it took three months to see a paediatrician. (SIS, 9 Polish 1)

4.13 This woman needed to see her GP several times to get a referral, she was disconcerted by the GP looking things up on the internet. She would like easier and **quicker access to tests and referrals** to specialists. (SIS, 11 Polish 3)

4.14 This group of three think the **wait to see a specialist from a referral is too long**. They would like to see **more specialists especially in GP surgeries** and **patients asked to confirm that they can attend appointments**. (SIS, 13 Portuguese 1)

4.15 This woman has experienced **long delays for ultrasound, x-rays and MRI scans** making a nine month delay between surgery and first seeing her GP. She would like a **central appointment system** rather than relying on letters. She would like to see more **specialists in GP surgeries**. (SIS, 14 Portuguese 2)

4.16 One of this group has had **great experiences of effective referrals from her GP**. She thinks this is because of her GP knows her well. She would like **longer appointment times with GP** to help understand the issues, **shorter waiting list with specialists** and **better communication between GP practices and hospitals**. (SIS, 20 Spanish)

"I was referred for 6 weeks of sessions only attended 4 because the therapist cancelled 2 due to sickness and wasn't offered anymore."
TDC 1 Interviewee

4.17 This group of 11, would like to be seen **locally by a GP rather than be referred to hospital**. They trust their GP and are in familiar and accessible surroundings. They would like **referrals to local hospitals rather than having to pay to go out of town**. They would like **more information about local community services**. (TDC 1)

Recurring themes

- Earlier referrals for tests and scans that are actioned
- Shorter waiting times for referrals
- Services delivered locally and more information about community services
- Improved appointment systems and better communication between GPs and hospitals

5. What we learnt: Preventing you ending up in A&E

22 people responded

Issues Raised

5.1 Y's cancer was only diagnosed after seeing a private specialist and she was immediately admitted to A&E for emergency surgery. Y would have liked **her repeated visits to A&E to have prompted further investigations**. She feels that this **misdiagnosis spanning many months meant that the cancer spread** and led to her current bleak outlook. (Age UK B&H, Cancer 1)

5.2 This person paid for a private scan and discovered she had stage 3 bowel cancer. She was admitted to the hospital immediately and an operation was conducted. **If the patient had waited for the NHS scan (she received a call to a scan 5 months later) the outcome may not have been as successful.** (Age UK B&H, Cancer 1)

5.3 Following poor treatment on a bank holiday, this woman would like the **main eye hospital A&E open on bank holidays with a duty doctor available and more training for the nurses** there. (Age UK B&H, Older People 3)

"Flare up of dry eye on a bank holiday. Old eye clinic was ancient and only had one nurse trying to cope single-handedly. Duty doctor hadn't turned up. Nurse was out of his depth. It was unhygienic, he put his finger in my eye, made matters worse."

Age UK B&H, Older People 3 Interviewee

5.4 This woman feels that her A&E visits would be better with a **greater understanding of her mental health difficulties** and if the environment were more enabling for her. (Age UK B&H, Older People 11)

5.5 This person initially called 111 and a GP home visit was advised. The GP was unable to visit or call so the person was taken by ambulance to A&E the following day. The person would like **better coordination between the 111 call system, doctor's surgery and the A&E department.** (Age UK B&H, Older People 12)

5.6 This woman would like **more information about alternatives to A&E services including pharmacy services and 111.** It would be good to know that 111 can be used by people who don't speak English well. (SIS, 9 Polish 1)

5.7 More knowledge about **alternatives to A&E services** would be good, especially pharmacists and 111 links with out of hours GP. Social media would work well to inform some migrant communities. (SIS, 9 Polish 3)

"A referral from the GP to a specialist or consultant sometimes takes forever and you don't hear anything to know what has happened. Maybe the letter is lost or forgotten - I don't know. I prefer to go to A&E and then wait to be seen by consultant. I am happy to wait there because it is only 4 hours and then I am confident that the specialist can see me and help me." SIS, 6 Farsi 2 Interviewee

5.8 More **information about alternatives to A&E such as health centres and 111.** (SIS, 14 Portuguese 2)

5.9 This group of three would like **less waiting and better assessment at A&E**. They have experiences of being sent home when not well enough. They suggested a “**pre A&E-service**” where people would be assessed to see if they needed to go to A&E. (SIS, 19 Spanish)

“I would always try to avoid A&E because the waiting is too long. Because of this the NHS is under pressure.” SIS 19 Spanish Interviewee

5.10 This group of 11 would like more **information to be widely available about what service to use and at what time**. In an emergency they would always go to hospital but use 111 first if not life threatening. (TDC 1)

Recurring themes

- Timely cancer diagnosis impacts on emergency admissions
- More coordination between services would reduce A&E visits
- More information about alternatives to A&E is needed

6. What we learnt: Keeping you out of hospital

21 people responded

Issues Raised

6.1 This person would like **earlier testing for cancer** as had she waited 5 months for a NHS scan her stage 3 bowel cancer would not have been detected early enough for treatment.

She would like her **GP to have taken her**

concerns more seriously, and for **better communication between doctors / surgeries and hospitals**. Patient history sharing is still a problem. (Age UK B&H Cancer 3)

"Y felt that if A&E had checked their records, they would have seen that her repeated visits should have merited further investigations into the causes for her pain. She feels that this misdiagnosis spanning many months meant that the cancer spread and led to her current bleak outlook." **Age UK B&H Cancer Researcher.**"

6.2 S would like **more walk in centres and minor injury clinics** to take the strain of A&E. **Convalescent homes** where people could go after hospital treatment would help reduce hospital stays. He thinks there is a **lack of communication between different services** which lead s to a disconnect in the way patients are treated (Age UK B&H Older People 10)

6.3 This disabled woman would like the **expansion of an outpatient advocacy service** to help keep her out of hospital. (Age UK B&H Older People 11)

6.4 This woman made every effort to avoid hospital but **calling an ambulance to go to A&E was the only way she could get the medical treatment** she needed. She would **better coordination between the 111 call system, doctor's surgery and the A& E department**. (Age UK B&H Older People 11)

6.5 This person would like **better communication about systems and processes** so that one is not left confused or unsure about how treatment will progress (Age UK B&H Older People 13)

6.6 This woman thinks that it is **essential to identify which operations can wait without becoming life threatening** and which tests should be carried out first. (Age UK B&H Older People 14)

6.7 This carer would like the **appropriate health care professional to see her family member so that a hospital referral can be made** if needed. (CW, PPG 2)

6.8 Following a hospital stay this person wasn't offered the necessary social care. She would like **hospitals and social care to be better connected** and for people to be made more aware of the services available. (SIS 21 Spanish)

6.9 This group of eleven would like there to be **a person to link up all the health services** and for **GPs to help more with referrals to services** that might help. (TDC 1)

Recurring themes

- Improved communication and connections between services is needed

7. What we learnt: Treating Mental Health Equally

35 people responded

Issues Raised

7.1 This woman feels that the local mental health services aren't fit for purpose because **care is limited for those that might periodically need it and that there isn't time for complex**

needs without it being an emergency. She would like to see a psychiatrist whose first language is English, and more beds for non-acute people. (Age UK B&H, Older People 5)

"It would be nice to see a psychiatrist whose mother tongue is English. Mental health facilities locally are not fit for purpose. The care is so limited for people who might periodically need it. I'm paying to see someone to get input I need (2 hour appointment)." Age UK B&H Older People 5 Interviewee

7.2 This woman would like to see **better assessment procedures at the beginning of treatment** for mental health problems as she feels that her daughter could have been helped much sooner, and without the medication. (Age UK B&H, Older People 9)

7.3 This man would like **more (and better trained) staff and hospitals to match the greater understanding of mental illness.** He would like the **police and other emergency services to have training in identifying mental distress and responding appropriately.** (Age UK B&H, Older People 10)

7.4 This woman would like **a comprehensive transport provider to and from hospital** that supports both her physical and mental health issues, so she can get to appointments. She would like a **designated outpatient's advocacy or support service** to help her manage her issues of cerebral palsy and bi-polar.

7.5 These eight young people felt that it was **awkward speaking to a GP** because they didn't know them and because of time pressures. They didn't like talking to councillors because it was uncomfortable talking about problems, two people had had **negative experiences of Child and Adolescent Mental Health Services (CAMHS)** one young woman had been seen once and offered some apps, she is currently withdrawing from social situations because of anxiety. Similarly, the **Youth Advice Centre was too awkward and difficult to access.** Six of the eight young people were **self medicating with Cannabis** to 'help' their mental health.

Instead they would like **more trusted adults such as community based youth workers**, this would help them access help and support quicker. **Youth shelters** were important as a place to go. **Local youth activities and residential** were identified as important ways gain support. The group felt that **councillors could use more creative techniques** such as doing a joint activity and that a **texting service would be good** (HKP, Younger People 1)

"It's awkward speaking to a person I don't know' and 'I feel pressured to say stuff quickly as I think they only have a few minutes to see me.'" HKP, Younger People 1 Interviewee

7.6 This group of three would like **earlier detection of mental health issues, less waiting times for CAMHS and a wider range of therapies available on the NHS.** (SIS, 22 Spanish)

7.7 This group of 11, felt that **social activities were really helpful for managing mental health.** They had made friends and offered mutual support. They felt that there should be **more than six sessions offered for mental health support and that buildings could be more accessible.**

“Therapy for anxiety and depression seems to be very limited. There is only CBT or counselling. These are good therapies but don’t work for everyone. Depression and anxiety are only treated when they’re really bad. They should be picked up earlier by GPs and there should be more preventive action.”
SIS 22 Spanish Interviewee

Community development workers could help with more local activities. Some had found the No Smoking service helpful. (TDC 1)

7.8 Members of this group of nine, had found it **difficult to get mental health support** for family members and would **like appointments more quickly.** They felt a **good social worker could make a huge difference** and they could be more specialised. (TDC 2)

“Have had a very difficult time getting support for my grandchild – often felt that the family is having to fight and argue for help when they should be getting support, makes the whole situation much harder for the whole family.”
TDC 2 Interviewee

Recurring themes

- Provision of mental health services in a timely and accessible way

8. What we learnt: Giving Children and Families a Better Start

31 people responded

Issues Raised

"I didn't interact with my social worker as they were in the position of authority and just told me what to do." HKP, Younger People 2 Interviewee

8.1 The **types of relationship social workers develop with young people** are a barrier to supporting their

engagement. There are issues around social workers taking too much authority, not listening effectively, not having enough time, and not being responsive. There is also a lack of continuity making it difficult to build trusted relationships. Solutions include more active and non-judgemental listening and social workers spending time doing a shared activity in order to build trust. Funding and support for positive family days would be helpful to develop family relationships too. (HKP, Young People 2)

8.2 It is **difficult to get a referral to hospital maternity services** so now ring directly or go straight there. The experience of care from midwives has been varied (CW, PPG 3)

8.3 This woman was surprised by the **lack of ill health prevention and screening services** in the UK and would like to see more emphasis on identifying and working with parents around childhood ill health issues. She appreciates the access to and manner of GPs and found maternity care excellent with choices offered and privacy respected. (SIS 3, English speaking Polish migrant)

8.4 This woman liked the opportunity to have a home birth, but no midwife was able to attend the delivery and no ambulance was able to transfer her to hospital. She would like to see **enough midwives to support all the home births**. (SIS 4, English speaking Spanish migrant)

8.5 This woman **didn't find her GP and health visitor particularly helpful around her daughter's issues**. She was **pleased with the maternity services**. She would like to see more support for parents around raising children and certain **vaccinations** to be compulsory. (SIS 10, Polish 2)

8.5 This woman is also concerned about the **low uptake of vaccinations** as well as **poor care for children with allergies and asthma**. She would like to see easier access to allergy tests and more accurate information about vaccinations for parents. She would like **migrants to be supported to get qualifications recognised** so they can work in the NHS. (SIS 11, Polish 3)

8.6 This woman has experienced poor health services for children with **medicines being prescribed with out testing or screening** and would like to see GPs requesting more test earlier. She thinks the **mental health services for young people could be improved**. She would like to see more **information about vaccinations** to increase their uptake. Again, she would like **migrants' qualifications to be recognised** in the UK and bursary places for medical students. (SIS 12, Polish 4)

8.7 These three women felt that **more support was needed around children with special needs before they start a new school** and better information provided about the help available. Schools need to be informed of special needs and to make sure support is available. (SIS 13, Portuguese 1)

“A report needs to be written for any child with special needs before they start a school so that the school can be prepared for this child. Alternatively, a place in a special school could be offered to the child.” SIS 13, Portuguese 1

8.8 This group of three really **liked the children centres, health visitors and schools**. One had found the **physiotherapy department at the Children’s Hospital great**. They would like to see **more information about services available in other languages**. (SIS 16, Spanish)

8.9 This group of 11 talked about the **waiting times and limited support time available from CAMHS** and would like to see easier access to services. They found **completing forms stressful** and would like more support with them. One person found **social services and health visitors helpful**. They would like to **more information about vaccinations** and a **more accessible, toddler friendly park**. (TDC 1)

“Social services and health visitors have been really helpful for me – people are usually scared of them, but they wouldn’t be involved if it wasn’t needed. They have helped me and are really nice.” TDC 1 Interviewee

Recurring themes

- Improve the relationships between young people and social workers
- More information about childhood vaccinations would help increase uptake

9. What we learnt: Sustainability and Transformation Partnership

1 person responded

Issues Raised

9.1 Patient has heard negative things about the STP and would like to be better informed about the implications (Age UK B&H, Older Person)

“The patient is very concerned about the NHS, has not heard of Caring Together. Has heard negative things about the STP but doesn’t understand what this is or what it means to her as a patient.” **Age UK B&H Older People 13 Researcher**

Appendices

This report summarised the interviews carried out by the community researcher in October, November and December 2017. For full details of the interviews please see the attached appendices.

1. Making it easier to see your GP
2. Helping you stay healthy
3. Making better use of medicines
4. Improving referrals from GP
5. Preventing you ending up in A&E
6. Keeping you out of hospital
7. Treating mental health equally
8. Giving children and families a better start
9. Sustainability and Transformation Partnership