

Lothian Voices

The People's Conference 2016:

Dear Doctor...



Stop



Amber



Go!

What people in Lothian with experience of mental health issues think about;

“How can your GP practice improve the way it works with you as someone who has experience of mental health issues?”

CAPS Independent Advocacy is a Scottish Charitable Incorporated Organisation (SCIO) Scottish Charity No SC021772

CAPS
independent
advocacy

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What is CAPS?

CAPS is an **independent advocacy organisation** for people who **use or have used mental health services**.

CAPS **works with people who use or have used mental health services** as individuals or as members of a group to **set their own agenda**, to find a **stronger voice**, to **get their point across**, and **influence decisions** which affect their lives.

CAPS provides individual and collective advocacy in **Midlothian and East Lothian**. CAPS also has several **Lothian-wide** experience-led projects.

Individual Advocacy is about working **alongside a person** to help them **express their views** and have more **influence over decisions** being made about their lives.

Collective Advocacy is about **groups** of individuals with a **common cause** who come together to **raise awareness**, **campaign** and **influence** service planning and provision.

CAPS is an **Independent Advocacy** organisation.

This means that it:

- Puts the people who use advocacy first
- Is accountable
- Is as free as it can be from conflicts of interest
- Is accessible

**CAPS is funded by East Lothian & Midlothian Councils
and NHS Lothian**

**CAPS is a Scottish Charitable Incorporated Organisation Scottish
Charity Number SC021772**

Who are Lothian Voices?

Lothian Voices are a collective advocacy group of people who gather together to give their views on NHS Lothian's Mental Health and Wellbeing Strategy. Lothian Voices is supported by CAPS. Every year they organise the People's Conference.

What is the People's Conference?

The People's Conference is a one-day inclusive event for people with lived experience of mental health issues in Lothian. It is a space where people feel safe, able and welcome to be honest about their lives.

Every year there is a stakeholder event about the NHS Lothian Mental Health and Wellbeing strategy. This event is called 'Taking Stock' and is organised by NHS Lothian. Anyone who has an interest in mental health services in Lothian can go to Taking Stock. The aim of Taking Stock is to look at what work has been done over the year and what still needs to be done.

CAPS organised The People's Conference because people who have lived experience of mental health issues told us that they would like more opportunities to give their views on NHS Lothian's Mental Health and Wellbeing Strategy.

Last year, the topic was "Working With All of Me" which involved looking at how services work with us holistically, with everything that is going on in our lives. Lothian Voices members decided the 2016 conference should look at people's experiences of using primary care services.

This year's topic:

How can your GP practice improve the way it works with you as someone who has experience of mental health issues?

Planning the People's Conference

The People's Conference steering group was open to anyone who identified as having their own experiences of mental health issues. The group had five members. Two staff members from CAPS were involved to help facilitate the meetings and actions coming out from the meetings.

The group decided that they wanted to focus on people's experiences of using primary care services.

We also talked about how we wanted people to feel at, and after, the conference, and what we wanted people to get out of it. The words that the steering group came up with in this conversation were:



Venue

A Sense of Someplace at the Walpole Hall was chosen as the venue again for the conference as people had largely welcomed this as a venue for the 2015 People's Conference.

The Conference

On the day, staff from CAPS Independent Advocacy facilitated the activities, with steering group members taking on the role of welcoming people to the event.

At the entryway of Walpole Hall, we asked people to write down their experiences of making appointments, dealing with receptionists and the waiting area.

During the morning, before coffee break, we worked in small groups with one facilitator at each table discussing;



What is good about your GP surgery?

Following the break in the same groups we continued discussions focusing on;

What could be better about your GP surgery?

After lunch people had the opportunity to develop Prescriptions for Change. We gave people the opportunity to use several methods of exploring these themes, from artistic methods to group discussion, to working alone.

We asked people to think about the morning's discussions and to identify what changes people thought would improve their experience with GPs.



What people said

When we looked at the responses from all the activities throughout the day we found that most of them could be gathered into five themes. The following pages give a summary of each category and what people told us would be their prescriptions for change:

• Access

To improve access, people think the following changes would make a big difference:

- Make it easier to book appointments by offering a choice - online, on the phone or in person. Remember that not everyone has a computer
- Offer more flexibility around making urgent appointments.
- Give us a choice about how much we have to tell receptionists when trying to make appointments, especially urgent appointments and double appointments.
- Make it easier to book double appointments. We find that appointments sometimes aren't long enough but asking for double appointments can be difficult. Some of us feel we don't deserve them or we worry that we will be thought of as time-wasting.
- Improve privacy in reception areas and provide breakout space. They can be too small, not private and too busy.
- We would like to know which GPs in the practice have a particular interest in mental health, it could be on the website and in practice leaflets.
- Some of us like getting text reminders about our prescriptions.
- We appreciate having different ways of getting information, for example, in accessible formats.
- Make it easier to register at a new practice; some practices have closed their lists and others only allow you to register at a set time and day of the week
- Give us easier access to our information, for example, share what is entered on the screen while we are in the appointment.

• Attitudes and Communication

The attitudes of GPs and how they communicate with us have a big impact on us.

- Listen.
- Take our physical health seriously and don't assume everything is because of our mental health problems. Diagnostic overshadowing is a problem for most of us.

"It is helpful] when the GP considers other things about your life too - person centred approach."

- Welcome advocates accompanying us to appointments.
- Allow us to communicate in ways which are easier for us e.g. listen to my advocate or read my list.
- Learn about us and our mental health problems over time because continuity of care is particularly important for us. We find having to tell our story over and over again difficult.

"My GP actually reads my notes so I don't have to retell my story which can be re-traumatising"

- Make us feel welcome, for example, come to reception to invite us to the consultation room, make eye contact and use our name.
- Consider other aspects of our lives such as our family circumstances, work, benefits situation etc.
- Offer alternatives to medication, such as talking therapies, community based support, exercise on prescription, etc.
- Ask us appropriate questions and consider whether they may be too intrusive or unnecessary.

"My doctor focuses on my mental health when I enter the room – [physical health] comes secondary to mental health. Feel I have had to really state my case about physical and mental health over and over and it's all through these 'bipolar tinted' glasses"

• Knowledge and Training

We think GPs need more knowledge and training about mental health problems:

“GP has learned over the course of working with me about mental health and has definitely improved.”

- Get more training delivered by people with lived experience.
- Learn more about what is available both within the NHS and in the community, in particular social prescribing, advocacy and welfare rights.
- Be aware of how trauma may have affected us.
- Be aware of how our mental health may fluctuate.
- Respect our understanding of our mental health issues even when it is different to yours.
- Provide lots of information on display in the waiting area.

“I know my Doctor communicates with my CPN/psychiatrist [which] is really helpful, means I don't need to keep repeating myself”

• Signposting

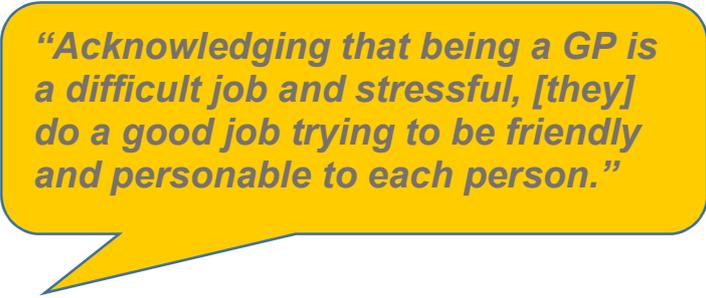
GPs are gatekeepers to other parts of the NHS and to other services. Increased knowledge and training means GPs will be able to signpost people more effectively

- Tell us about services such as counselling, drop-ins, welfare rights, and advocacy.
- Offer us more support to help us while we are on long waiting lists for secondary services.
- Refer us to specialist help more quickly and appropriately e.g. trauma services, physical health services.
- Write informative letters for the DWP.



"GP very helpful with letter for ESA"

• Resources



"Acknowledging that being a GP is a difficult job and stressful, [they] do a good job trying to be friendly and personable to each person."

We are very aware of the problems GPs face, for example there are too few of them and many are part-time so there are too many locums. We know they are busy and work long days, that they are stressed and that they have too much pressure on them to meet targets and to prescribe cheaper medication.

This affects us in many ways - in particular, it is hard for many of us to see the same GP when we need to so this means there isn't the continuity of care that we value.

Employ more GPs, practice nurses and support staff in GP practices.

- Base peer support workers and information workers in GP practices.
- Provide more preventative services.

Conclusion

People with lived experience of mental health issues value good, ongoing and respectful relationships with GPs.

They are the first point of contact with the NHS and gatekeeper to secondary services. We appreciate that it is a difficult job and that primary care is under stress.

However, the suggestions we have made would improve services and the experiences of both GPs and patients

Feedback from the event



Our original word cloud described the words that we would like people to describe as their experience of the day.

People told us that they valued the opportunity to come together in a **welcoming** space. That they felt **Listened to** and that the opportunities for **networking** in a **safe** environment were valued.....but that the acoustics and heating were still an issue!

Next Steps



At the end of the People's Conference, all attendees were invited to join the steering group to take the work of the conference on. Since the conference, the steering group has been making sure that the language in the priorities and solutions was as simple as possible, and removing any repeated points.

The experiences collected in this report were presented by people from the steering group for the People's Conference at Taking Stock in May 2016.

We then produced a briefing in response to the demand for the findings. This report is based on the briefing.

We are already looking ahead to organising a People's Conference 2017. Please get in contact with jane@capsadvocacy.org or on 0131 273 5116 if you are interested in keeping up to date with news of this conference and/or being on the steering group for it.

Getting involved will be flexible around what suits you, but could be with all stages of the process, for example, deciding what we do, organizing events, running events or activities, writing up reports, giving presentations about the events, doing illustrations, or simply giving your opinions.





Acknowledgements

CAPS would like to thank everyone who was involved in the planning, collaboration and organisation of the steering group.

For all those who attended and participated in this year's People's Conference, CAPS would like to thank you for your enthusiasm and involvement. It was great to see so many people attending and we look forward to seeing everybody in the future!

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