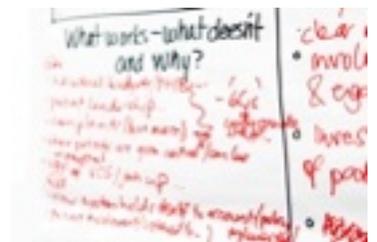


Healthwatch England

Special Inquiry Hosted Conversation

Arlington Conference Centre
London

22nd
September
2014



Welcome

Anna Bradley, Chair of Healthwatch England, warmly welcomed everyone to this first public event of the special inquiry. *“The aim of today is to bring together health and care system leaders, local Healthwatch groups and service providers with people with direct experience of being discharged from health and social care services.*

This inquiry has focused on unsafe discharge, particularly amongst people who are homeless, those with mental health conditions and older people.

“We want to share some of the findings from our inquiry and together co-create some solutions to the challenges that have been surfaced. We wanted to take a new approach, to be engaging and participative not to simply put a towel over our heads in a dark room and come up with just our ideas. So please join in and engage with the group throughout the course of the day and let’s come up with some unique recommendations that lead to real change.”



Linda Mitchell and Sarah Whiteley from the Art of Hosting introduced the flow of the day, inviting people to slow down, to listen and to pay attention to the many perspectives in the room. *“What are the patterns and threads that are the clue to the future? Where is the collective wisdom and intelligence that we need to move forward?* Following a ‘hands up’ to see the diversity of people present, we moved to a ‘check in’ where small groups introduced themselves and spoke about why they were here today and what they were hoping from the day.

Some people spoke of concern over uneven treatment from fragmented services, others of their desire to have their voices heard in the policy making arena. There were concerns about the current state of health and social care services and the effect this had on vulnerable individuals. Also a desire to ensure that organisations in the system didn’t ‘defend their positions’ but instead actively engaged to try and solve issues rather than widen the gaps in provision.



Creative Presentations - Inquiry Stories

Marc Bush Director of Policy and Intelligence at Healthwatch England gave an overview of where the special inquiry had got to and explained how they had been out and about hearing about lots of problems but also lots of good practice. He told three stories to illustrate some of the things they had heard:

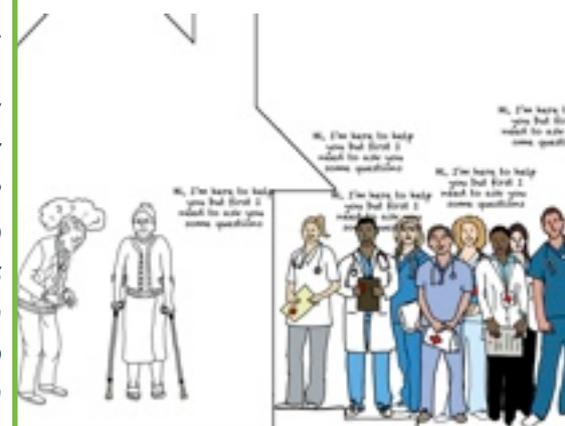


Tracy was being discharged from hospital. Her psychiatrist with good intentions had become fixated on the idea of her getting a dog to support her continued recovery. All Tracy wanted to think about was integrating back into society and getting her son back (who had been put into care). She felt that the psychiatrist was not listening to her and had become fixated with the need for her to have a dog. Many people found having a dog useful upon discharge but for Tracy this was not going to work for her, the thought of having to care for a dog was causing undue stress. This is representative of many others that have not felt listened to, have not been treated as an individual, what will work for them. Although many healthcare workers make efforts to involve the individual in decision-making, sometimes they are asking the wrong questions.



Mike was a Homeless man receiving chemotherapy approved for self-care and discharged to a flat (temporary accommodation). Discharged with three large bags of medication he had no idea what to do with or when. The homeless outreach nurse had to wait three hours in the housing department to find out the address. She had to break into the flat which had no heating and found him shivering in a thin fleece, soaking wet, he couldn't swallow properly or feed himself.

Valerie thought that when discharged she would be entitled to the same six week re-ablement package she received after her first hip replacement 2 years earlier. Instead she was discharged without any care plan or support whatsoever. As sole carer for her elderly husband with dementia, she had the additional concern for her husband's welfare during the recovery phase. *"They left me standing in my kitchen, supported by 2 crutches... I am no wimp but on that afternoon I was devastated. Even now, several weeks on, I find it difficult to talk about it without crying. It took from Wednesday to the following Monday (and lots of phone calls) to get a care plan working. During this time I was vulnerable and in serious danger of needing to be re-admitted to hospital."*



Story Telling

“It was those who really cared who made the difference.”

After a coffee break we entered a session of user led storytelling, hearing real stories about the impact of unsafe discharge. The other attendees were invited to listen out for different threads and patterns across the stories in order to later debrief and share the learning from these personal experiences. The threads were:

- ◆ What went wrong and why did it go wrong?
- ◆ What does the storyteller think could have prevented it from going wrong?
- ◆ How involved was the storyteller in decisions made about them?
- ◆ What support were they offered?
- ◆ What emotions did the storyteller feel throughout their experience?
- ◆ What were the outcomes that the story teller wanted?

All three storytellers were invited to speak about what had happened to them, how it had made them feel, how involved they had felt in their care and discharge plan and what might have helped or made their experience a better one.

All three spoke with great honesty about some painful experiences of not finding the right levels of support during discharge, being discharged onto the street with nowhere to go and little follow up, issues with medication and lack of

One person spoke of the difference between *“the staff who were rubbish and those who made a real difference. It was those who really cared who made the difference. Nothing huge, just caring. Like when I had a nurse join me once when I was discharged so I had company. Would’ve made things better if there was more continuity in care in the community. I’m worried that policies and paperwork stop people from caring. Not always the case but it does cause problems when people are more focused on targets and paperwork”*.

Thanking the story tellers for sharing their experiences in front of such a large group, Linda asked for some initial comments or reactions from the listeners. *“If people ever needed a reminder of why people who work in health and social care do their jobs, these stories should be that”*. Listeners also spoke about the way the ‘system’ categorizes people and defines people by their conditions, they’re then always treated as an ‘alcoholic’ or ‘self-harmer’, the label never goes away. *“Don’t define me by my illness or behaviour, this confines me to a box that makes it difficult to break free of.”*



The listeners thanked the story tellers for really telling some of the reality on the ground and expressed hope that some change would come from this. The story tellers said it had been a pleasure to have a voice and how important it was to be heard and understood.

Harvesting the themes from the stories

The listeners then gathered in small theme groups to share their impressions of the stories and the themes they had been listening out for. They were also invited to identify the key leverage points for positive change, things that

could turn these stories round and reframe them into something more desirable.

Following a lively conversation, each group then fed back their impressions and key points in plenary.

A full record of this is found at **Appendix A**. Here are some snippets of what was spoken:

- People hadn't previously appreciated how fragile the continuity of care is and they were surprised that small breakdowns in people's experience could add up and lead to the crises we heard about.

- System designers and professionals lamented that they have talked so long about person-centred design, but in reality the way things are structured (commissioning and rules) doesn't allow for the flexibility and innovation that is needed - they were worried that this had led to the people we heard from leaving when they were 'medically fit', but were not adequately prepared - and because of professional specialism people don't see patients in the round.

- One of the keys seemed to be about the quality of relationships. As soon as individuals had a crisis they got moved on and had to develop new relationships all.

- One group's reflection on the stories was that we need to train people to be able to

change gear when things could be about to go wrong (like not having support in the community) and to make sure the system was flexible enough to allow for this change in speed.

- In some cases where professionals have decided that a course of care/medication is right then unless consumers speak up its considered tacit approval. Often individuals are not informed, brave, or confident enough to raise their voice. There isn't necessarily active listening. We need a systemic cultural change to actively listen. We don't need to create more policies, we need to alter existing behaviours and perspectives.

- Users need to have the bravery to come forward as they are exemplars of unspoken and future stories, but it can't all sit on the shoulders of users. The system doesn't provide the support and sometimes advocacy which could help them to raise their voices. Given where the system sits now, there is no place for advocacy.



Leverage points for safer discharge

- Better alignment of incentives
- Joining up people's needs, key workers to see people through the process
- Point of admission is crucial - to find out where people are coming from and what their expectations were
- Empowerment - ensuring people have a voice or advocacy, ensuring that people are able to speak or where unable to, they are able to access someone who can help
- More Listening
- Human connection - not 'passing the buck'. How can we instil hope?
- Being given more opportunities to be involved and to speak out
- Including opportunities right at the start of the user engagement to share where people are coming from
- Ensuring that mental health diagnoses/care plans are done at an early stage

Design for wiser approach

Following a break for lunch and more conversation Katherine Rake CEO of Healthwatch England introduced the afternoon session. *"Sometimes you need to look at where you have got to in the whole and see where things have been biased and then intervene. There are a lot of policy people in the room so we will have a tendency to want to rush to the recommendations. But we still need to be in enquiry mode as well as problem solving mode. When we say we need more compassion, what does that actually mean? And how can we actually make that happen?"*

She invited us into the afternoon design challenge where anything we suggested now should also be something that would make a

The four challenges were:

- People don't have the information they need or understand their rights and entitlements

- People are not treated in a dignified and compassionate way and are made to feel responsible for system failings

difference to the people we heard from earlier. We were also asked to consider opportunities to amend the existing offers not to reinvent the wheel.

Linda explained the 4 design challenges that had arisen from the special inquiry and invited people to choose to work in one of them for the rest of the afternoon; choosing a group where they felt that could make the best contribution or a topic they were most passionate about making a difference.



- People experience services as disconnected

- People are not as involved as they should be

Linda asked if there were additional design challenges that had come through this morning that people wanted to work on and two more were raised:

- It's not just about how you go out (discharge), but also how you go in (admission)

- How can we take into consideration how wider society views individuals with a variety of specific vulnerabilities and tackle this?/How does society view vulnerable people (labelling)?

The challenge for the afternoon was to work together to firstly think about the existing provision/suggestions that should help to address this challenge and to discuss what worked well and what didn't, then to consider the relevant leverage points from the story telling session, and finally to generate some ideas and recommendations that would lead to better outcomes both for the story tellers and for service users in general.

Groups got to work on their challenges and harvested their findings on ready-made templates. Linda explained the law of two feet, inviting people to take responsibility for their participation and to move around groups and join different conversations, cross pollinating ideas and solutions.



Plenary feedback session - bringing it all together

Each design group fed back the key points from their deliberations and the recommendations were spoken and harvested real time onto the graphic map. A full record of the 6 templates can be found at **Appendix B**. The following is a list of the recommendations that came from each of the design groups:

Design Challenge 1: People don't have the information they need or understand their rights and entitlements.

There should be a consumer care role so that consumers feel supported: a social care worker role to ensure people go back into community with the information they need.

We need to ensure consistent delivery of social care assessments.

There should be CAB advisors/representatives of appropriate specialist third sector organisations embedded in institutions to tell people rights and responsibilities to help apply for benefits.

We should monitor that the mandatory requirements for assessments and support roles are undertaken and implemented.

NICE is developing 3 guidelines on the transition of care and the CQC should use these guidelines in their inspection process.



Design Challenge 2: People are not being treated in a dignified and compassionate way and feel responsible for system failings.

Training for all staff using positive and negative service users' stories, challenging stigmas and using 'expert by experience' trainers.

Being honest - Not making promises that cannot be kept and being honest about when promises are not kept. Services are under pressure and we need to be honest about that. We can't always deliver what we'd like to deliver so if we are honest about it at least then staff can have a dialogue about it with consumers. Ensuring that consumers are aware and that available information is shared.

Ensuring that staff morale is maintained. There should always be capacity provided to ensure that frontline staff have the supervision and support they need to take the time to treat customers in a dignified and compassionate way.

We need to build compassionate organisations.

Design Challenge 3: People aren't involved in the way they should be.

Ensure that people have the incentives, flexibility and permission to be able to replicate good practice and 'break the rules'.

Joint commissioning that enhances integration needs to be incentivised, not just 'commissioning' that creates fragmentation.

Ensure that individuals hold their own information and use it to translate it across the system. Putting the information about their care into their own hands.

Care navigators for the system should be created. These people should be present from admission to discharge (and onward) to ensure continuity.

A national clearing house should be set up to deal with issues that have no home.

Establish a mechanism to ensure that issues are dealt with at the right level - either nationally, regionally or locally (or a combination of).



Design Challenge 4: People experience services as disconnected.

There needs to be clear metrics around involvement, participation and engagement of patients - that can be accountable and reported on at a local level.

There needs to be investment in the development of patient leadership.

Consumers should be supported in maximising self-governance where possible: Individuals should know more about opportunities and to signpost opportunities for them to make decisions about their care.

There should be increased provision for wider reablement mechanisms e.g. activities, lifestyles - what else can I do?

There should be individualised community support - befrienders or experts by experience to provide direct support to consumers as they navigate the system.

Design Challenge 5: It's not about how you come out, it's about how you go in.

Ensure that before people enter the system there are services with spaces where service providers can identify individual histories and needs. In order to capture the right information at an early stage in their care.

Professionals should have the opportunity to identify and fix rules where they are not working - occasionally suspending rules where necessary.

There should be increased access to peer support and consumer advocacy.

Greater exposure for GPs and front line professionals to the experiences of people in vulnerable situations. Space should be created for staff training and development opportunities in this area.

Services should be commissioned using multidisciplinary models that are being codified - not reinventing the wheel, incorporating new approaches that are proven to work in specific cases where existing formalised commissioning approaches do not include these variations.

Aligning incentives to positive experiential outcomes for users rather than other system drivers.

Design Challenge 6: How does society view vulnerable people (labelling)?

Extra training for new doctors and nurses - especially in issues around homelessness and substance misuse.

Grassroots advocacy should be highlighted - people prioritised over profit. Especially in the housing sector where provision is not driven by user needs.

There needs to be more/better representation of vulnerable groups in mainstream/ social media. To combat the perception amongst these groups that they are forgotten/ deliberately hidden/neglected/not listened to and to escalate these issues for action across the system and in wider society.

There should be proactive campaigns to address stigmatised groups e.g. obese young people should be helped and encouraged to exercise to avoid being stigmatised later in life which can lead to mental health issues. Prioritising campaigns around children and young people will improve outcomes later both for individuals who suffer stigmatisation but also for the perception of these individuals across society - improving society.

There should be improved rights to access social housing provision and access to affordable housing.

There should be a re-prioritisation of funding to ensure that funding is maintained to all services. Niche services are often very important to what may be a small number of vulnerable individuals who use them but this is not always seen through statistical evidence.

Thank you / Close and next steps



Anna Bradley closed the session by thanking everyone for their input and commenting that Healthwatch England had received so much more than we had expected. She explained what would happen now with the inquiry - that ultimately it would be reporting to the Secretary of State and the system and calling for responses. A report will be produced but this is just the beginning of the process - Healthwatch will be following up both nationally and locally to help ensure changes are put in place.



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For more information on the processes used in this seminar, please visit www.artofhosting.org
Report designed by Valerie Menelec.