Storytelling: the 3Ss of co-production

Shaping through storytelling

What support do we offer when people are telling their stories?

Coalition for Personalised Care

Background

Some of our most successful ways of communicating the current reality of Personalised Care are through people sharing their stories. These stories may be examples of successful Personalised Care, or where the lack of Personalised Care has had an impact on someone's quality of life.

A lot of big health and social care events invite people with lived experience to share their stories alone or alongside presentations by professionals. This session focuses on ways to support the people who are telling their stories.

Some of the key questions we can ask are:

- Who are the storytellers?
- Why do they tell their story?
- How do we offer emotional support when people tell and share their stories?
- Do we provide someone to offer immediate support, or do we signpost?
- Is signposting adequate?
- Do we need to offer specialised advice and support?

> *The impact of someone sharing their story may not just be in the moment but may impact their experience of their condition, social situation and contact with medical settings as they move forward.*
>
> Katie Clarke-Day – Coalition for Personalised Care

Presentation

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Key points:

Stewardship – this is our term for caring for the individual. We want to build genuine relationships with the people that we work with. We value authenticity and that's why people value their relationship with us.

Expectation management – volunteers are equal and experts in their own self, we can only control what we can control and we are clear about what we can't.

Valuing the storyteller – communicating the impact and value of someone's story is important, as well as thanking them and acknowledging their input. We have internal reward and recognition programmes such as 'flame of hope' and there are external ones like the 'pride of Britain'.

Respect – we have to be careful about 'commoditising' content once it's been produced. We need to guard against content getting used indiscriminately.

Trust – the relationship with the people that are telling their stories is important. Having structure and systems in place is the best way to support them, with robust informed consent.

Safeguarding – if you see that someone needs help to signpost them in the right direction for the support that they need.

Boundaries – help people who may be impacted by listening to the stories.

Follow-up questions:

Q: What database do you use to keep track of the stories told by your volunteers?

A: We use MS Dynamics. This may be too large for most people's needs, you basically just need to be able to tag, filter and search. Happy to discuss details if you would like to contact me directly.

Q: How would you deal with an individual who might be wearing something inappropriate whilst being recorded?

A: You need to address this kind of thing diplomatically, one phrase I use is 'we don't want to mix messages.' Being honest and authentic helps to build a strong relationship.

Discussion

Participants collaborated in breakout rooms to answer the following questions.

The answers were collated on this Jamboard.

What sort of support do people need to tell their stories?

- A safe space – somewhere the storyteller feels comfortable and secure.
- Empathy – people need someone to listen to them, ideally with experience in providing mental health first aid and/or patient experience issues.
- Emotional support – provided at all stages: before, during and after storytelling activities.
- Personalised support – activities should be flexible to accommodate people's individual needs such as bringing a support person. Support needs might also be different depending on where someone is at in their journey – if they are in the middle of treatment or at the end of their treatment journey for example. Stories can also change as the journey progresses.
- Accessibility – checking in with the storyteller on the best ways for them to communicate, and choosing a medium which is comfortable for them.
- Validation – acknowledging the value of the story and the importance of it being heard.
- Respect – stories are always true for the people telling them, so it's important to stay true to the story and share any edits for approval by the storyteller.
- Trust – building a strong and authentic relationship with the storyteller.
- Consent – being explicit in the ways/channels through which a story might be published and giving storytellers the chance to veto or choose anonymity.

Emotional and practical support for people during their preparation of what they are going to say, during the time when they are sharing their story, and during a debrief afterwards.

Who provides the support needed?

- Everyone involved needs to be aware of potential support needs.
- Safeguarding teams should always be available.
- Local or peer support groups might provide the best support – there is a need for more of these.
- There are questions around what is meant by 'support' and who is ultimately responsible.
- Having professional boundaries in place and regular supervision will enable those hearing stories to be supported.
- Regional and national VCSEs such as:
    - Mind
    - Mental Health First Aid
    - Storytelling training
    - Samaritans
    - Access to Work
    - Healthwatch
    - Marie Curie
    - Macmillian
    - End of life care organisations
    - Bliss (neonatal care charity)
    - Independent living group

Everyone involved has a role to play in support.

What limitations are there around providing an appropriate level of support?

- Time – clinical and professional demands may mean support provision is limited by capacity or working hours.
- Resources – staffing issues may impact the ability to provide support, particularly if an experienced staff member leaves.
- Funding – financial issues may impact the capacity to provide support.
- System pressures – lack of policy detail or low prioritisation of co-production activities.
- Skills – staff may need to develop expertise and experience in providing support.
- Uncertainty – storyteller may feel unsure or unable to share the need for support.
- Changing circumstances – storyteller may develop a later need for support, or have changing needs for support over time due to personal circumstances.

We are not a 24/7 service so support is limited to working hours.

Any other comments/ reflections?

- Sometimes the people running the meeting haven't really thought about what they really want from the person participating, and sometimes this can lead to people being exposed to disturbing or upsetting clinical information. For this reason, we suggest providing guidelines for inviting people to meetings. This would include questions like:
    - Have they seen the agenda, is it appropriate for a storyteller to attend?
    - Could they attend for just part of the meeting?
    - What questions do you want answered? Could these be provided in a statement?
- We practice 'wrap-around care' – making sure that storytellers are OK and that the door is open at the end. We explain their rights as a storyteller and that they can always remove consent in the future if they change their mind. We have a routine and a structure so that we thank and recognise the storyteller once they have 'gone public'.
- An individual story can't necessarily be generalised/representative of an entire community/population.

Resources

Listen, Learn, Lead – digital patient storytelling programme – Royal Brompton and Harefield hospitals (Twitter @HopeNetworkNHS)