



Guidance for Collecting & Using People's Stories

Published 27th August 2014

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1. Introduction

Collecting people's stories is integral to all we do as a local Healthwatch. We are committed to relentlessly championing people's voices in the health and social care system and to build an evidence base that we can use to help inform service improvement. In building this evidence base, Healthwatch Cambridgeshire will work closely with communities, their representatives and networks, all commissioners and providers of services and other statutory partners.

Healthwatch Cambridgeshire will ensure that its staff and volunteers have the skills, knowledge and resources necessary to collect stories in the safest and most appropriate way. Thorough understanding of the principles of confidentiality and safeguarding will be key, as will non-judgmental approaches and a good understanding of equality and diversity. This document sets out a framework that will ensure that we collect and use stories sensitively, effectively and accurately, placing the person at the centre of all we do.

2. Guiding Principles

Stories are powerful. People's stories have the power to keep individual's experience at the centre of consideration, to influence decision makers and to promote positive change. The storytelling process can also be powerful and emotional for the storyteller and the story taker.

The storyteller leads. The people sharing their stories with us determine the order and flow of the storytelling process. They are in charge of what they share with us and what we are allowed to share with others.

The story taker supports the storyteller. We will help the people sharing with us by asking questions and recording their stories in a manner that suits them. We will provide information about how and why stories will be used and provide referrals for follow-up support when useful.

Confidentiality is essential. We will get consent before sharing any personal information with anyone outside of Healthwatch Cambridgeshire, unless it is necessary to prevent harm to someone.

3. Using People's Stories

Healthwatch Evidence Base

Healthwatch Cambridgeshire will collate people's stories and identify themes or trends over time. We will share this intelligence, anonymised appropriately, with commissioners, regulators and the people who provide the services, to make organisations aware of how services are being experienced and how they can be improved. We will let people know how their story has been used and how it has been of benefit when possible.

We will escalate unresolved local issues to Healthwatch England and other influential bodies, for example Health Overview and Scrutiny or the Health and Wellbeing Board. The impact and outcomes of our work will be reported regularly to our Board, Commissioner and Healthwatch England.

Expectations of Trusts

It is recognised good practice for Trusts to start their governance meetings with a Patient Story. Trusts should ensure that these stories are collected, heard and actioned in accordance with the good practice set out in this document. Guidance for Trusts should recognise that:

- Stories should be collected sensitively using the skills and insight set out in this guidance
- Telling their stories may be difficult for people and they may need support before, during and after their stories are told and heard
- Trusts should record and follow up actions taken as a result of hearing the story
- The impact of these actions should be fed back to the storyteller
- Trusts need to ensure that the storyteller is fully aware that their story may be heard by members of the public and press and that good practice principles of confidentiality are ensured at all times

Staff development

People's stories are a powerful tool to help staff see how people experience the services they deliver and to gain insight and understanding of people's feelings. Many organisations are starting to use this approach in their workforce development. The King's Fund have developed an Experience-based Co-design Toolkit specifically for this purpose¹.

¹ <http://www.kingsfund.org.uk/projects/ebcd/experience-based-co-design-description>

4. Skills & Attributes

Healthwatch Cambridgeshire will help staff and volunteers develop appropriate skills required to collect people's experiences. When recruiting staff and volunteers, we will emphasise the essential attributes of sensitivity and being non-judgemental and promote opportunities to develop the required skills to collect stories in a safe and professional manner. These are some of the key skills and attributes for effective and safe story collecting:

Effective Communication

- Attentive Listening
- Skilled Questioning
- Astute Observation

Professional Attitude

- Awareness of professional scope
- Practices within boundaries
- Ability to recognise issues that need to be addressed outside of the interview

Enthusiasm for the project

- Empathy towards people's experiences
- Commitment to service improvement

Emotional Maturity

- Reflective practitioner
- Objectivity
- Impartiality
- Personal reflection and insight

Awareness

- Sensitivity to environment and atmosphere
- Adherence to Lone Worker Policy

Healthwatch Cambridgeshire appreciates the value of developing these skills and is keen to advise and assist groups and organisations on collecting stories, with a view to developing a package of training for staff and volunteers.

5. Confidentiality & Consent

People's stories are individual and personal. By their nature, stories about someone's experience of health and care will contain sensitive personal information that needs to be securely stored and used in line with Data Protection law. If people are to feel confident in sharing their stories, they need to know that the information will be held securely and used in accordance with their stated wishes.

For some people's stories, it will be easy to anonymise their experiences and share them without disclosure of their identities. However, for many people, the detail of their story will be enough to identify the people concerned even if names are

not given. Asking for consent to share in advance of using any person's story is an important part of respecting the person and their experience, as well as complying with the law.

Collecting people's experiences is essential for Healthwatch to be able to do its job. A balance is therefore necessary to gather as much experience as possible whilst making sure we respect people's wishes and comply with Data Protection and Healthwatch Cambridgeshire Confidentiality principles. Guidance for staff and volunteers is set out in the Healthwatch Cambridgeshire Information Governance, Data Protection and Confidentiality policies. (A sample consent form can be found at Appendix A).

Staff and volunteers need to ensure that:

- All hard copy personal information will be kept securely and will be accessible only to those who need to see it
- All electronic information will be kept in designated folders and protected by passwords and firewalls, as appropriate
- Personal information will only be kept on mobile devices, ie laptops, phones, tablets or external drives, with appropriate security/encryption
- Information will be factual
- Permissions will be sought from individuals regarding the use of their data and that data will only ever be used for that specified purpose
- Further consent will be needed if the information is to be used for a different purpose other than the purpose it was originally collected for
- We will not keep personal information any longer than needed
- It is everyone's responsibility to ensure that confidentiality is maintained both inside and outside work
- Where it is necessary to transmit personal information electronically, only secure communication methods will be used

Staff and volunteers need to be mindful of confidentiality; consent may not be required if they have reason to believe that a person is at risk of harm. Full procedures are set out in Healthwatch Cambridgeshire's Safeguarding Policies.

6. Keeping Safe

Before undertaking any work with people to collect stories, all staff and volunteers must be clear about our role in safeguarding. Healthwatch Cambridgeshire has comprehensive guidance for staff, managers and volunteers in its Safeguarding policies. It is essential that all staff and volunteers are familiar with the principles, process and sources of help and support set out in these policies. Everyone must be aware of what to do if they hear anything that alarms them or gives them reason to believe that someone may be at risk of abuse.

Keeping staff and volunteers safe is important too. Everyone needs to be aware that recording people's stories can be an emotional experience, and that they should use regular supervision sessions to debrief and request further emotional support should they feel that would be helpful.

Healthwatch Cambridgeshire's Lone Working policy states that visiting people's homes should only be done in exceptional circumstances and approval needs to be given by the CEO. Every effort should be made to find a suitable location, such as a local community or health centre, for the interview to take place. If someone's home is the only suitable option, then it is advised to arrange to have family or carers present.

7. Formats & Inclusivity

In order to meet the needs of a diverse community, we must be prepared to collect stories in a variety of settings and offering a number of recording formats.

Currently, we collect people's stories in the following ways:

- Telephone conversation with a member of the Healthwatch Cambridgeshire team
- Email
- Electronic submission via our website
- Face to face contact with a member of the team, as recorded by the team member
- Submission of a 'Tell Us Your Story' form (Appendix B), either in person, online, or via free post, as written by the individual submitting the story

Stories submitted in any of these formats are added to our Experiences and Concerns Log.

These formats may be sufficient for short or quickly recorded experiences, as well as when the person sharing the story feels they are adequate. Some of these experiences may require follow up by a team member.

Helping People to tell Their Stories

Any individual can elect to tell us their story in a format with which they feel comfortable. People can also contact us to say they have a story to share, and we may suggest a variety of formats to help them share their story.

We also need to create opportunities for people across Cambridgeshire to tell us their stories. These may include:

- Outreach events
- Attending community meetings already in place
- Creating story telling events, including focus groups, listening events, and organised creative projects

Recording Methods

For the collection of stories, the following formats should be considered:

- Audio recording
- Video recording
- Individual self-record
- Interview, as recorded by the Healthwatch team member
- Other potential creative outlets, including photography, poetry, documentary, collage, as submitted by the individual

Audio Recording

Audio recording is, for many people, an unobtrusive way to record a person's story. As long as the person is aware that the conversation is being recorded, the digital recorder can allow the person to share their story unimpeded, as well as being the most reliable record of a conversation available.

Video Recording

Whilst video recording offers the same accuracy of recording as audio recording, a video recorder may be more likely to put a person off and influence the story they are trying to tell. Video recording should be considered when there is a specific reason for recording body language, gesture or posturing, when it is the preferred medium for the person sharing their story, and when the final (or interim) goal is a video itself. Video recording (or the video equivalent of a selfie) may appeal to certain groups as a specific project, as well.

Manual recording

Self-record by the individual telling the story gives the story teller ultimate control and an accurate recording of what the individual wants to share. For individuals confident with their story and their writing skills, this is a very strong format.

Note taking, by either the interviewer or an observer, is an easy, accessible format for recording, and someone with strong listening and recording skills can take a very accurate record of a story. If listening and recording skills are not strong, another medium should be considered. The person telling the story may be influenced by responding to the recorder's note taking.

Other Creative Outlets

Photography, collage, poetry, documentary, community mapping, investigative journalism, and other creative outlets may offer fantastic opportunities to collect peoples' stories. These mediums may be more difficult to interpret, but they may also be more able to capture the intended audience's attention. These methods may require more forward planning and more specific resources.

8. Practical Tips

***'Taking a story could be compared to talking to a friend. You listen, prompt them to continue at times, or explain something differently to aid understanding. It is not your role to give your opinion, advice or recommendation; it is your role to help the storyteller talk.'*²**

- Make sure that the person telling their story understands why you want to hear what they have to say. Be realistic in explaining the consequences of recording their story, you cannot promise change, recompense or that apologies will be made.
- Make sure that you get consent from the story teller before you start. Respect the story teller's wish to remain anonymous if that is the case, respect their confidentiality where appropriate (see section 5).
- Be clear that Healthwatch Cambridgeshire cannot undertake case work or help pursue a complaint but can put them in touch with organisations that can.
- Make sure the story teller understands that if you hear something that puts others at risk, you will have to do something further with that information (see section 6).
- Do not put the story teller under any pressure to tell their story. Make sure that the story teller is comfortable and able to talk. Where possible the person taking the story should not be someone involved in providing direct care to the patient, either in the past, present or in the future.

²<http://www.1000livesplus.wales.nhs.uk/sitesplus/documents/1011/T4I%20%286%29%20Learning%20to%20use%20Patient%20stories%20%28Feb%202011%29%20Web.pdf>

- If you can, try not to be too linear in your thoughts. If the patient/carer wants to start in the middle of their journey or deviates from the anticipated path this is how their mind works.
- If something which obviously has importance to the person crops up then you will need to be flexible and allow them to explore that aspect.
- Use open questions starting with what, why, how, who, when and feel. 'Tell me about' is a useful prompt.
- Listen out for cues, such as the tone of voice not matching the words. This might require further exploration.
- Be sensitive to silence, if they are quiet it is an indication that they are thinking, reflecting or collecting their thoughts: try not to fill the silence they will speak again when they are ready.
- If you notice that they are upset, tone doesn't match voice etc. ask them how they are feeling about what they have just said, for example "you are sounding quite cross at the moment".
- Allow the story teller to stop at any time.
- Clarify as you go through the session. If you are not sure what someone is saying it is perfectly acceptable to ask for clarification
- Don't steer away from asking how they felt about something. Be aware that people will not automatically share their feelings. While someone may have very positive things to say about their treatment and care they may equally have felt confused, isolated and afraid but unless you give them an opportunity to talk about that you will never know.
- Ensure that the story teller has all the information that they may need should they wish to make a complaint or send a compliments about the service they have received. Signpost to organisations able to offer support with the complaint process if appropriate.
- Think about support during and after the story is taken if needed. Discuss with the story-teller what support they have and if necessary help them get some support from, for example, local voluntary and community organisations.
- Thank the story teller, for their story and their time.
- When recording the story, ensure that integrity of the story is respected throughout - do not alter it in any way which does not reflect the story and the spirit in which it is given.

9. Further Reading

Working with Stories by Cynthis Kurtz:

<http://www.workingwithstories.org/WWSPrePubCompleteDec2013.pdf>

Patient and Family-Centred Care Toolkit, The King's Fund:

<http://www.kingsfund.org.uk/projects/pfcc/patient-stories>

Using patient stories for service improvement:

http://www.health.wa.gov.au/hrit/docs/A_toolkit_for_collecting_and_using_patient_stories.pdf

People's stories about genetic conditions:

<http://www.tellingstories.nhs.uk/>

The use of digital stories in healthcare education:

<http://www.patientvoices.org.uk/about.htm>

Online sharing of stories aimed at helping people learn about and manage their health conditions:

<http://patientmemoirs.com/>

Consent to share your story

We want to share your story to help improve health and social care services.

Your story belongs to you. We will only share those parts of your story that you have told us we can share.

We will not share your name, contact details, or full postcode.

We may share your story in a public report or a public presentation. All our public reports will be available from our website.

We may share your story with the people who make decisions about local health & social care services.

Please initial any of the following options that you agree with:

I am happy for my story to be shared.

I would like to see a draft of any written material that shares my story before it becomes public.

There are parts of my story that I do not want you to share. *(Please use the back of this form to tell us more about this or speak to a Healthwatch Cambridgeshire member of staff.)*

I understand that I can withdraw my consent for Healthwatch Cambridgeshire to use my story at any time.

In some cases, we would like to contact you to ask if we can use your story for a different purpose or if we can include more detail. To do this we need to hold your contact details.

You may withdraw your consent for us to hold use your story or hold your contact details at any time.

If you are under 16 years, we may need to talk to the person who cares for you, before we can share your story.

We will never give away or sell your contact details.

Your contact details

Your Name*

Your signature

Date

Telephone

Email

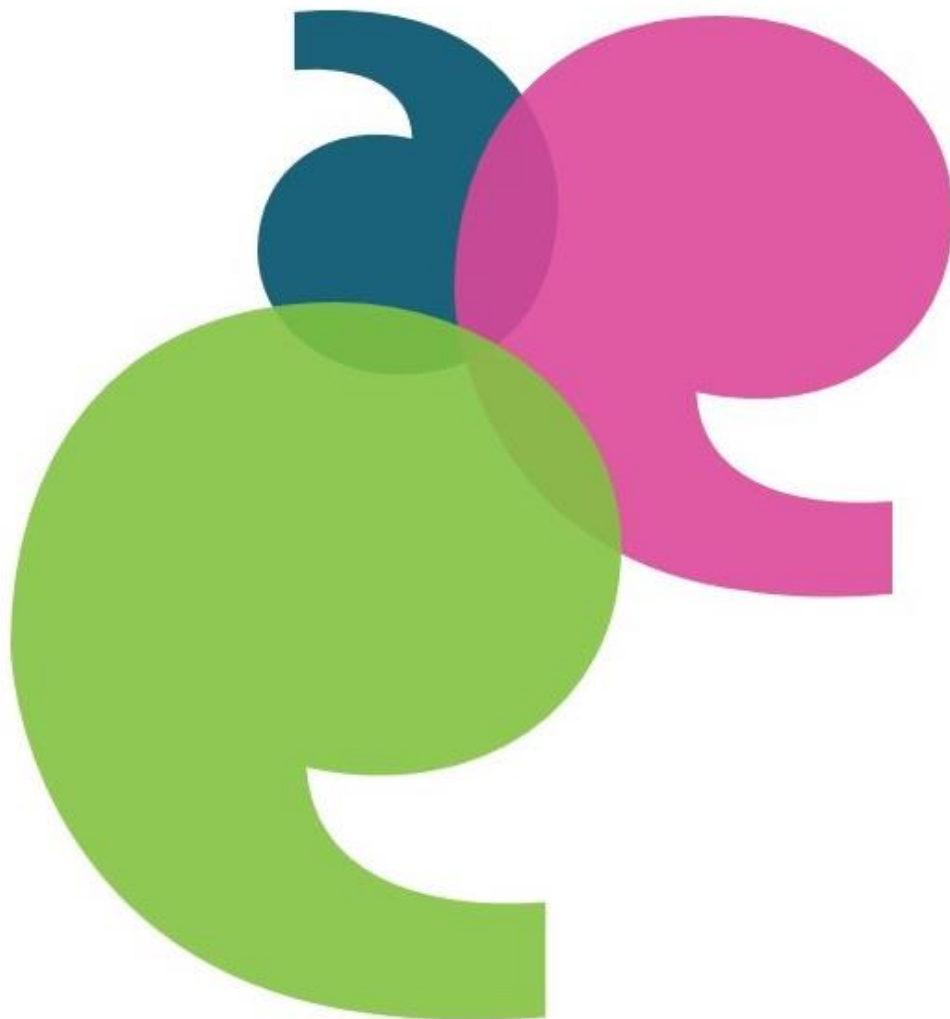
Tell us your story

Healthwatch Cambridgeshire gathers views on local health and social care services to help local people have their say about what could be changed or improved.

We want to hear your story of using health or social care services in Cambridgeshire.

We may share this information with Healthwatch England and with local commissioners or providers of services. This will be done in a way that does not identify you personally.

Name		Date	
Where do you live? (eg Huntingdon)			
What service are you telling us about? (Name and address, if possible)			
When did you receive/use this service?			
Was your experience	😊 good	😐 mixed	😞 poor?
Tell us your story (please continue overleaf if necessary)			
If you want us to contact you about what you have told us, please provide us with a phone number or email address:			
You may post your form to Healthwatch at the following address: Freepost RTHA-RTYE-SATT, Healthwatch Cambridgeshire, 6 Oak Drive, HUNTINGDON, PE29 7HN			




**Working with you to improve
health & care in Cambridgeshire.**

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