

# Listen Learn Act

Harnessing the power of  
personal stories to drive  
service improvement

Information and guidance for  
staff on story-gathering



***“...if we are serious about driving up standards it is clear there is a need to give patients a louder, more systematised voice which would tell us what we need to know about our performance...”***

N.G. Dewhurst  
President, Royal College of Physicians of Edinburgh  
25 February 2013

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## Foreword

Across the UK, there is growing awareness of the need for care providers to engage directly with service users and for staff to monitor their experience. Using individuals' personal stories helps to drive continual improvement and ensure that care is effective, relevant and high quality.

Stories are narrative accounts that help us make sense and develop a better understanding of events that happen to ourselves and others. The American Professor Brené Brown of the University of Houston Graduate College of Social Work describes personal stories as "data with a soul". And there are growing calls for directly-reported patient, carer and staff experience to be used more systematically to promote care quality improvement.

In his final report on the Mid-Staffordshire NHS Foundation Trust Public Inquiry (published 6 February 2013) Robert Francis QC made direct reference to the serious failure of the Trust Board to "listen sufficiently to its patients and staff or ensure the correction of deficiencies brought to the Trust's attention".

The provision of person-centred care is at the heart of NHSScotland's quality ambitions. That cannot be achieved without listening to the experience of patients and staff, learning from it and, most crucially, acting upon that learning.

In its response to the Francis Inquiry report, the Royal College of Physicians of Edinburgh calls for renewed attention to be paid to patient feedback. In an editorial in the *Journal of the Royal College of Physicians of Edinburgh* (published 25 February 2013), RCPE President N.G. Dewhurst writes: "...if we are serious about driving up standards it is clear there is a need to give patients a louder, more systematised voice which would tell us what we need to know about our performance at the institutional level before it started to seriously fail."

While it is widely recognised that patient and staff surveys and traditional feedback systems have an important place in improving quality in person-centred care, it is also evident that even more needs to be done to enlist the help of frontline providers and recipients of care by learning directly from their first-hand experience.

In the Mid-Staffs report, Robert Francis QC called for fast-track reporting of patient experience:

*"Results and analysis of patient feedback including qualitative information need to be made available to all stakeholders in as near 'real time' as possible, even if later adjustments have to be made."*

Social media platforms including Twitter, Facebook and dedicated internet sites such as Patient Opinion present exciting new avenues for patients, carers and staff to connect directly with health and care providers. There is an immediacy to these, and other emerging digital communication tools, that cannot be matched by more conventional feedback mechanisms.

Using social media poses challenges to care providers who have tended to use them to broadcast information rather than to receive it.

Meanwhile, it is important to continue to develop a wide range of effective ways to capture patient, carer, service user and staff experience. Their stories are vital for service improvement.

This guidance on recording personal stories has been produced in response to requests for support from across the service. It contains practical advice, and provides useful links to a wide range of resources.

If you have any questions, comments or feedback, please contact Jane Davies, Educational Projects Manager: [jane.davies@nes.scot.nhs.uk](mailto:jane.davies@nes.scot.nhs.uk) or Angela McCulloch, Project Co-ordinator: [angela.mcculloch@nes.scot.nhs.uk](mailto:angela.mcculloch@nes.scot.nhs.uk) or 0141 223 1608.

NHS Education for Scotland  
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## Introduction

Nothing beats hearing the first-hand experience of patients, carers and staff to communicate learning points about the way care is delivered. People's feelings, expressed by them directly as storytellers, inspire understanding and empathy, and encourage service providers to listen, learn, and act upon what they are told.

The purpose of story-gathering in this context therefore is to provide clear learning points that can be reflected upon and applied in order to provide better person-centred care.

Storytellers must be properly supported to share their personal experiences in clear and constructive ways that inform service development. By doing so, they know they are taking part in the vital process of continuous improvement of care.

Increasingly, recorded patient, carer and staff stories are being used to educate and inform practice in health and social care. However there are important aspects of the story-gathering process that must be taken into consideration by everyone involved.

This guidance:

- outlines the benefits of person-centred story-gathering
- explores the skills required to gather personal stories
- considers legal and ethical issues associated with NHS story-gathering
- highlights the principles of good governance that must underpin such work
- shares best practice
- supports staff to ensure that the information shared by patients, their carers and colleagues produces positive results, both for the service and for the individuals involved

The information that follows is based on research and a growing body of experience. It includes references to a wide range of sources, and presents examples of resources that can be used to support local story-gathering work.

## Resources

The King's Fund (2011), *The Patient-centred Care Project: Evaluation report*  
[www.kingsfund.org.uk/ebcdreport](http://www.kingsfund.org.uk/ebcdreport)

*Journal of Research in Nursing*, vol 16, No.1 - Dewar B, Mackay R, Smith S, Pullin S and Tocher R (2010) 'Use of emotional touchpoints as a method of tapping into the experience of receiving compassionate care in a hospital setting'.

*Quality and Safety in Health Care*, vol 15, No. 5, pp 307–10 - Bate SP and Robert G (2006) 'Experience-based design: from redesigning the system around the patient to co-designing services with the patient'.



## Background

There is evidence that, when they are properly gathered and used, personal stories empower storytellers. People who share their experience, and know how the learning from their stories has been applied, feel that they have been positively involved in service development and improvement. Organisations that use stories to improve services develop a culture of participation and a reputation for listening and acting upon what they learn.

But it is clear that story-gathering has to be structured. There must be an identifiable purpose to asking people to share their personal experiences, and their participation in the process has to be properly supported.

The professionals involved in story-gathering must have the skills and knowledge to perform the task well, and organisational capacity has to be established and maintained.

## Before you start

Story-gathering must be meaningful. It must not be tokenistic or manipulated to suit a service. There has to be an identified purpose and an anticipated outcome that can be clearly explained to participants.

Planning should start early and involve the wider project team: depending on the reason for story-gathering, that team might include practitioners, service planners, patient representatives and third sector colleagues.

Collectively the team should be specifying what they want to know more about and identifying to what use the personal story information will be put: who will hear it, how will they hear it, and what might the outcome be. That information should then be communicated to potential storytellers in an appropriate format, recognising and responding to the individual needs of the person.

Consideration must be given to the recruitment of storytellers: do you involve patient representative organisations, or do you approach individual patients, carers or staff and, if so, at what point in their care journey? There may be ethical issues associated with contacting people receiving care or immediately post-discharge from care, and a multi-disciplinary team approach is recommended to fully explore such questions. If you are unclear about this you should speak to your Information Governance Manager or Caldicott Guardian.

Enough time has to be built in to the process to ensure that the storytellers' needs can be fully met. Full consideration must be given to any support needed to enable people to tell their story. This means considering any language barriers, communication support needs, cultural, literacy or age barriers or any other issue that could get in the way of people being able to share their story. This might mean enlisting the help of patient advocates, foreign language translators or sign language interpreters.

The information you want to gather should be clearly identified and simple questions drafted to ensure that key points are covered. You may, for instance, want to follow a patient's journey through a care system: relevant prompts can help both the story-gatherer and the storyteller to stay on track.

Project specific story-gathering guidelines should be drafted and easily-accessible participation information and consent forms prepared. There are resources that can be adapted to suit specific projects. These include the Social Care Research Ethics Committee (SCIE) Good Practice Guidelines for Information Sheets and Consent Forms. There is more information on consent in the relevant section of this guidance and from the Little Things Make a Big Difference website [www.knowledge.scot.nhs.uk/making-a-difference.aspx](http://www.knowledge.scot.nhs.uk/making-a-difference.aspx).

## Resources

The King's Fund, *Experience-based co-design, developing your project plan – includes sample project timeline* [www.kingsfund.org.uk/ebcd/project\\_plan.html](http://www.kingsfund.org.uk/ebcd/project_plan.html)

NHS Institute for Innovation and Improvement *project management guide*  
[www.institute.nhs.uk/quality\\_and\\_service\\_improvement\\_tools/quality\\_and\\_service\\_improvement\\_tools/project\\_management\\_guide.html](http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/project_management_guide.html)

GMC, *Making and using visual and audio recordings of patients*  
[www.gmc-uk.org/guidance/ethical\\_guidance/making\\_audiovisual.asp](http://www.gmc-uk.org/guidance/ethical_guidance/making_audiovisual.asp)

The King's Fund, *Experience-based co-design, sample patient interview schedule*  
[www.kingsfund.org.uk/ebcd/interviewing.html](http://www.kingsfund.org.uk/ebcd/interviewing.html)

INVOLVE, *A guide to actively involving young people in research*  
[www.conres.co.uk/pdfs/Involving\\_Young\\_People\\_in\\_Research\\_151104\\_FINAL.pdf](http://www.conres.co.uk/pdfs/Involving_Young_People_in_Research_151104_FINAL.pdf)

SCIE, *Good Practice Guidelines for Information Sheets and Consent Forms*  
[www.screc.org.uk/files/information sheets and consent forms.pdf](http://www.screc.org.uk/files/information sheets and consent forms.pdf)

NHS Education for Scotland, *sample photographic and video consent form*  
[www.nes.scot.nhs.uk/media/861293/combined\\_consent\\_form.pdf](http://www.nes.scot.nhs.uk/media/861293/combined_consent_form.pdf)

## Recording methods

There are many ways to record personal stories. Each story must be given freely, highlighting learning points as identified by storytellers. They must be recorded fully, and any extracts must not be used out of context.

- **Written stories** – Individuals can be interviewed face-to-face or by telephone or via internet connection, and their experience written up later. For that the story-gatherer may either use shorthand, employ the services of a scribe, or take verbatim longhand notes and transcribe the interview from those. A story could also be sent to the organisation by the individual already written up. This may take the form of feedback or a complaint. These stories can still be used as learning points – properly anonymised and the appropriate consent sought for use.
- **Audio recordings** – With the storyteller's permission, and informed consent, the conversation can be audio recorded and that recording transcribed, if needs be. Alternatively, full recordings, or clips of recordings, could be used to share the story.
- **Video recordings** – Again, with the storyteller's informed consent, the interview can be recorded on film. This is more technically challenging, requiring camera and sound recording equipment and perhaps lighting, but it is certainly the most powerful medium for communicating storytellers' feelings.

## Resources

*Health and Social Care in the Community* (2011), 19(3), 326-334 'Young people's views on sharing health-related stories on the internet' – Juping Yu, Nicki Taverner, Kim Madden, Genomics Policy Unit, University of Glamorgan

<http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2010.00987.x/abstract>

The King's Fund, *Experience-based co-design online resource*  
[www.kingsfund.org.uk/ebcd/is\\_ecbd\\_for\\_you.html](http://www.kingsfund.org.uk/ebcd/is_ecbd_for_you.html)

Department for Education, *Building a culture of participation, handbook* [www.education.gov.uk/publications/standard/\\_arc\\_Positiveactivitiesvolunteering/Page1/DfES/0826/2003](http://www.education.gov.uk/publications/standard/_arc_Positiveactivitiesvolunteering/Page1/DfES/0826/2003)

*Nurse Educator* 28(5), 217-221, 'Storytelling as a teaching technique' – Davidhizar R & Lonser G (2003)

*Nurse Education in Practice* 7(3), 181-186, 'Storytelling: a clinical application for undergraduate nursing students' – Schwartz M & Abbott A (2007)

Better Together, *Experience based design cancer pilots, interim reflection report* (2011)  
[www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/1008115/EBD%20CancerPilots%20InterimReflection%20Report%20Version1.0.pdf](http://www.knowledge.scot.nhs.uk/media/CLT/ResourceUploads/1008115/EBD%20CancerPilots%20InterimReflection%20Report%20Version1.0.pdf)



### Story-gathering skills

Story-gathering is not a precise science. Some people are naturally good at it, and others can be taught. Good communication skills require self-awareness: it is helpful to observe how others listen to you, and how that feels; consider how you communicate in everyday situations and continually practice 'active listening'. As a story gatherer, there are some useful principles to apply:

#### Active listening

- **Create a comfortable atmosphere** – Do your utmost to put the speaker at ease, taking the time necessary to do that before the interview begins. Demonstrate respect for them as individuals, and show genuine interest in the story they have to tell.
- **Minimise distractions** – Turn off the TV or radio, do not fiddle with pens or papers, and encourage full concentration on the task in hand.
- **Pay attention** – Face the speaker directly. Be conscious of your body language: do not cross your arms, which indicates defensiveness; do not fidget. Sit up straight or even lean in towards the speaker to communicate interest and engagement. Maintain eye contact, if that feels comfortable.
- **Support the speaker** – Responding to the speaker while they are talking with nods and supportive facial expressions encourages them to continue. Smile, if that is appropriate. Avoid indicating judgement of the speaker, and resist interrupting or using 'hmms' and 'uh-huhs'.
- **Focus solely on the speaker** – Do not lose concentration or allow your thoughts to drift off.
- **Leave yourself out of it** – Your role is to hear what you are being told, not to offer advice or share your experiences. Only volunteer personal information if you are asked.
- **Never get defensive** – No matter what you are being told, do not take it personally, and do not attempt to justify. Beware of defensive body language.
- **Reflect on what you are hearing** – At appropriate points, and without interrupting the speaker, check that you are understanding what they are saying. Paraphrase what you have heard and check if that is correct.
- **Clarify** – If you are in any doubt about a point that is being raised clarify with the speaker.
- **Summarise** – It may be necessary to summarise what you are hearing to check that you understand what someone is really saying. Ask the speaker to summarise the points they are making and be prepared to hear the story again. Do not be tempted to direct the storyteller or influence what they say or how they say it.

## Resources

The Royal College of Nursing, *Communicating with patients, relatives and colleagues*  
[http://www.rcn.org.uk/development/health\\_care\\_support\\_workers/hca\\_and\\_ap\\_newsletter/tools\\_of\\_the\\_trade/communicating\\_with\\_patients,\\_relatives\\_and\\_colleagues](http://www.rcn.org.uk/development/health_care_support_workers/hca_and_ap_newsletter/tools_of_the_trade/communicating_with_patients,_relatives_and_colleagues)

*How Healthcare Professionals in Scotland develop their communication skills, attitudes and behaviours, An independent report for NHS Education for Scotland*  
[http://www.nes.scot.nhs.uk/media/547484/long-term\\_conditions-communication-and-human-relationships.pdf](http://www.nes.scot.nhs.uk/media/547484/long-term_conditions-communication-and-human-relationships.pdf)

The Health Experiences Research Group at the University of Oxford runs training courses on filming interviews and other qualitative methods [www.herg.org.uk](http://www.herg.org.uk)

The King's Fund, *Experience-based co-design, Interviewing and filming patients – includes interview guide* [www.kingsfund.org.uk/ebcd/interviewing.html](http://www.kingsfund.org.uk/ebcd/interviewing.html)

## Recruiting storytellers

It is important to establish that the story each storyteller has to tell is relevant to the project in hand. That is done by speaking individually to each potential storyteller prior to recording, and exploring what they might have to say.

Storytellers may need help to clearly identify the elements of their stories that provide learning points. Story-gatherers must always remember that it is what matters to service users and staff about their experience that is important, and that these have to be highlighted. Stories need to have a beginning, middle and end for them to be complete and emphasis should be on what will assist service improvement and make a difference to services for both patients and/or staff.

It is necessary to approach storytellers at the right time. For instance, if they are patients or carers with experience of being in hospital, the right time may be just before discharge or soon after. For staff, this may be after a particular episode of care or incident in the workplace. Some people may feel vulnerable sharing negative experiences in the care setting or while they are still receiving care or just after an incident has occurred and they may prefer to wait. Everyone must be given the opportunity to consider a request to share their experience, to reflect on their experience for a period of time if they wish, and be allowed to specify when story-gathering should happen.

Once storytellers have been identified, they should be given all the information they need to equip them to make a decision about whether or not they wish to participate. Their explicit and informed consent must be given and clearly recorded. Story-gatherers should develop information and consent forms to suit specific projects.

Some examples of such resources are accessible via the links and contacts shown in the panel at the end of this section. For instance, NHSScotland has prepared a consent form for photographic and video materials.

At every stage of the process you should be reconsidering any barriers to storytelling and ensuring that appropriate supports are in place to enable storytelling.

Depending upon the purpose of the story-gathering, and the individual storytellers involved, it will be necessary to consider ethical issues and information governance. Taking into account local consent issues, local project teams will be required to develop project consent forms for the entire process. This may need to be broken down into different stages and consent sought at each stage.

Storytellers should be encouraged to ask any questions, and supported to consider the pros and cons of taking part. Pros might include helping to make things better for future service users, while cons might include being identifiable.

Potential storytellers may need to be given assurances that the experiences they share, or a decision not to take part, will not compromise any care they may be receiving, or any future care they might receive, or a decision not to take part, and story-gatherers must respect any requests for anonymity. This may mean using another name for a storyteller, disguising a voice, using an actor to voice over the storyteller's words, or obscuring their face on film.

If a potential storyteller decides not to take part, that decision must be respected. If, however, they agree to proceed the story-gatherer must make every effort to ensure that participation is made as easy as possible.

What is involved in participation – where the interview will take place, how it will be recorded, what will happen to that recording, and how it will be stored and shared – should be communicated clearly according to individual needs.

It may be helpful to the storyteller to be given the outline questions, in advance of the storytelling taking place. This may help them to think about what they wish to say.

Storytellers should be given the opportunity to review the information they have shared, and they should have the right to have any part or all of it removed if they wish.

### Resources

*NHSScotland photographic and video consent form*

[www.nes.scot.nhs.uk/media/861293/combined\\_consent\\_form.pdf](http://www.nes.scot.nhs.uk/media/861293/combined_consent_form.pdf)

*Essential CAMHS resource* <http://www.nes.scot.nhs.uk/education-and-training/by-discipline/psychology/multiprofessional-psychology/essential-camhs.aspx>

*Essential CAMHS Filming Participation Information Leaflet*, available on the NES Knowledge Network website, Little Things Make a Big Difference  
[www.knowledge.scot.nhs.uk/making-a-difference.aspx](http://www.knowledge.scot.nhs.uk/making-a-difference.aspx)

*Essential CAMHS Filming 2 stage consent forms*, available on Little Things Make a Big Difference website [www.knowledge.scot.nhs.uk/making-a-difference.aspx](http://www.knowledge.scot.nhs.uk/making-a-difference.aspx)

*SCIE, Good Practice Guidelines for Information Sheets and Consent Forms*  
[www.screc.org.uk/files/information-sheets-and-consent-forms.pdf](http://www.screc.org.uk/files/information-sheets-and-consent-forms.pdf)

NHS National Patient Safety Agency, *National Research Ethics Service guidance on information sheets*  
<http://nuhrise.org/wp-content/uploads/NRES-Guidance-on-Information-Sheets-and-Consent-Forms.pdf>

## Consent

It is vital that storytellers give explicit informed consent to the recording of their story – whether the story is to be recorded in writing, by audio or video. This is to protect the interests of the storyteller as well as the story-gatherer and the organisation they represent.

Consent forms should specify clearly in what formats the story will be used – as audio or video recordings, on paper, or electronically via the internet. The groups of people who may access the stories should also be specified: for instance, NHS staff, social care staff, managers, service planners, students, external organisations, other storytellers, the general public (locally, nationally, internationally), patients and/or carers.

Consent forms should confirm that the storyteller has understood the information they have been given about the purpose of the story-gathering, and that they have had the opportunity to ask questions. Storytellers must also be made aware that they can change their mind and withdraw consent, although any limitations on this must be explained. For example, it may be feasible to withdraw an online resource when consent is withdrawn, but it may not be possible to withdraw a widely distributed booklet, DVD or CD-Rom.

Consent may be time-limited or indefinite, but that should be specified. The record of consent must be retained for as long as the resource is in use. Where the storyteller is a patient remember that the consent record, as well as the story itself, if it is not anonymous is Patient Identifiable Information. See the section on Data Protection for more details on the implications of this.

Storytellers whose experience will be shared in print or as audio should be asked whether they would prefer to share their story anonymously, or whether they wish to be given another name, or have their words repeated by an actor. If the interview is to be captured on video, they should be asked whether they are willing to be seen in vision, or whether they want their image to be obscured during the editing process. They should be given the opportunity to review their answers to consent questions whenever they choose.

If the story is to be used for any purpose beyond that originally consented to, new consent must be sought. Storytellers should always receive copies of their consent forms.

## Resources

*NHSScotland video consent form*

[www.nes.scot.nhs.uk/media/861293/combined\\_consent\\_form.pdf](http://www.nes.scot.nhs.uk/media/861293/combined_consent_form.pdf)

*NHSScotland Code of Practice on Protecting Patient Confidentiality*

<http://www.ehealth.scot.nhs.uk/wp-content/documents/nhs-code-of-practice-on-protecting-patient-confidentiality.pdf>

General Medical Council *'Making and using visual and audio recordings of patients'* April 2011

[http://www.gmc-uk.org/guidance/ethical\\_guidance/making\\_audiovisual.asp](http://www.gmc-uk.org/guidance/ethical_guidance/making_audiovisual.asp)

*Adults with Incapacity (Scotland) Act 2000 – information*

<http://www.scotland.gov.uk/Publications/2006/03/07090322/0>

<http://www.mwscot.org.uk/the-law/adults-with-incapacity-act/>

*Psychiatric Bulletin* 2002, 26: 117-118 'Consent, rights and choices in health care for children and young people: by the British Medical Association', Angela Hassiotis [pb.rcpsych.org](http://pb.rcpsych.org)

## Consent from children, adolescents and vulnerable adults

In some cases, where a storyteller's age or competence to consent may be an issue, the consent of a carer, parent or guardian will be required. When it comes to working with children, young people and vulnerable adults, the advice is to seek the consent of both the child, young person or vulnerable adult and their parent, guardian or carer. The process of consent, how it is facilitated, and who provides it for vulnerable people, has to be very carefully thought through.

## Disclosure

Different types of disclosure may be required by staff involved in story-gathering depending on the nature of contact they will have with service users when recording stories. All staff in direct contact with patients and service users will require appropriate checks. Each Health Board has a system in place to facilitate these checks.

People who work with vulnerable groups are required to register with Disclosure Scotland's Protecting Vulnerable Groups scheme.

### Resources

*Disclosure Scotland PVG scheme information*

[http://www.disclosurescotland.co.uk/pvg/pvg\\_index.html](http://www.disclosurescotland.co.uk/pvg/pvg_index.html)

## Contact information

It is imperative that full and accurate contact information is gathered for storytellers. This is important for review of information, and in case of the need for permission to be given to extend the use of the story at some future time.

It is also vital that storytellers have good contact information for the individual gathering their story and the organisation that they represent. This is necessary should the storyteller have further questions, or wish to amend or withdraw permission for their story to be used.

## Management of expectation

While every effort must be made to use recorded stories in full, storytellers must be made aware that extracts of their story may be shared, for instance in edited compilations. This should be made explicit at the outset. However, if extracts are used, they should be set in the context of the full story and not misrepresented in any way.

In recognition of the time they have given to share their story, storytellers should be given a full recording or transcript. They should be invited to review the information they have shared and asked to consider if they wish any part of it removed.

If the recording is edited, the storyteller should again be given the chance to review what they have shared. They should be reminded that they can withdraw their consent at any point.

### Arranging recording of a personal story

Unless it is done by telephone or online, a decision will have to be made about where the storyteller and the story-gatherer will meet to capture the story.

It may be most appropriate, and easiest for all concerned, to record service user and staff stories in the care setting. Alternatively, it may suit the storyteller if the recording is done in their home or a place of their choosing. The story-gatherer must consider their own safety and, if appropriate, observe rules about lone working and risk assessment, but where possible they should be willing to fit in with the preferences of the storyteller.

Storytellers may wish to be accompanied by a friend, carer or guardian. In relation to filming vulnerable people, children and young people, all filming should include at least two people drawn from appropriately qualified members of staff working with the individuals, familiar support from any partner organisation if available, and carer/guardians.

If the story is to be recorded on film, it is worth visiting the place where the recording will happen in advance. There has to be enough power sockets available to run recording equipment, and the lighting has to be adequate. Test filming will establish whether extra lighting or special sound recording equipment is required.

It may be helpful to the storyteller to be given prompt questions, in advance of the story-gathering taking place. This may help them to think about what they wish to say and also to consider what the learning points are.

The recording of any detailed personal story is likely to take some time and staff should ensure they set aside enough time to do this. It is important to make sure that there are refreshments available and any other support needs have been considered and addressed.

#### Resources

The King's Fund, *Experience-based co-design, interviewing and filming patients – includes sample interview schedule and HERG guide to filming interviews*

<http://www.kingsfund.org.uk/ebcd/interviewing.html>

### Confidentiality

It may be necessary to involve external professional camera crew in video recordings, or to contract the services of an external video editor, and it is essential that such contractors observe the rules of patient confidentiality and have necessary checks carried out. This should be made explicit in contracts.

#### Resources

GMC *confidentiality guidance*

[www.gmc-uk.org/guidance/ethical\\_guidance/confidentiality.asp](http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality.asp)

NHSScotland *Code of Practice on Protecting Patient Confidentiality*

<http://www.ehealth.scot.nhs.uk/wp-content/documents/nhs-code-of-practice-on-protecting-patient-confidentiality.pdf>



### During the interview

The story-gatherer should have introduced themselves to the storyteller in advance of the interview taking place, and will have scoped what the storyteller wishes to say and the key learning points they wish to share.

Before recording begins, the story-gatherer should check that the storyteller is still willing to share their experience, and that they understand the purpose to which their story will be put.

As detailed in the story-gathering skills section of this guidance, the story-gatherer's role is not to express an opinion, contradict the storyteller or give advice: it is simply to support the storyteller to communicate their key points in a clear manner, and to ensure that the areas outlined in the interview schedule are addressed.

The story-gatherer must display respect, empathy and care, and be sensitive to the needs of the storyteller. If, for instance, they require a break, or start to become distressed, the story-gatherer must respond appropriately.

If the storyteller is distressed by the experience of recounting their story, the story-gatherer should be able to offer emotional support, or ensure that appropriate support is available if required.

### Resources

The King's Fund, *Experience-based co-design, Interviewing and filming patients – includes interview guide* [www.kingsfund.org.uk/ebcd/interviewing.html](http://www.kingsfund.org.uk/ebcd/interviewing.html)

### After the interview

Storytellers must be thanked for their valuable participation – preferably in writing. They must be assured that they will have the chance to review what they have said, and that they will be kept informed about the use of their story. In some cases, storytellers (and their carers) may wish to be involved in the whole process, including the editing of film clips, which should be arranged.

Storytellers must be supplied with accurate contact information for the story-gatherer, and any relevant people within the organisation using their story, should they wish to ask questions or withdraw consent for their story to be used.

### Feedback

Following consideration of their story, storytellers – whether they are patients, carers, or members of staff – should be kept informed about the use to which the information they shared has been put. For instance, if a story has led to a service or practice improvement, the storyteller should receive that feedback.

## Data protection

All personal data created during the collection of stories (including consent records, transcripts, audio and video recordings) must be stored and used in accordance with the Data Protection Act 1998. The story may only be used for the purposes for which informed consent has been given.

All the data must be protected from access other than by authorised staff. Measures to protect the data may include secure network storage areas only accessible to authorised staff, the use of locked cabinets for paper and other media, secure disposal of data when it is no longer required and the use of encrypted storage and recording devices. You must always comply with your local policies for handling and storing personal data.

For any new patient story projects or procedures, you may need to obtain consent from the Caldicott Guardian for your NHS Board. Contact your Board Information Governance Manager for details.

Where staff involved in handling patient data (such as patients' consent forms or story recordings) are not registered clinicians, they will be classified as Healthcare Support Workers and subject to the relevant standards for the purposes of this story-gathering.

### Resources

Scottish Government NHSScotland *Caldicott Guardian's Principles into Practice 2010*  
<http://www.scotland.gov.uk/Resource/Doc/340362/0112733.pdf>

Scottish Government *eHealth Mobile Data Protection Standard 2008*  
<http://www.ehealth.scot.nhs.uk/wp-content/documents/mobile-data-protection-standard-pdf3.pdf>

Scottish Government *Healthcare Support Workers Standards 2010*  
<http://www.hcswtoolkit.nes.scot.nhs.uk/hcsw-standards-and-codes/>

*Data Protection Act 1998* <https://www.gov.uk/data-protection/the-data-protection-act>

## Resources required

Story-gathering and recording is time intensive, and can be demanding of resources. The story-gatherer has to ensure that they can dedicate sufficient time to support each storyteller. If external professional expertise, such as translation, transcription, film production, camera and sound recording or editing is required, that has to be included in project costings.

Similarly, if there are recording and editing skills on the project team, it may be necessary to purchase or rent equipment and software.

It is good practice to ensure that storytellers are reimbursed any out-of-pocket expenses for travel, etc. It may be necessary to consider counselling support if the process of relating their experiences may cause distress for the storyteller.

Good project planning should identify such costs. But when story-gathering works well, it yields benefits for services that far outweigh the costs. Then, storytelling becomes truly cost-effective and enhances quality of care.

### Resources

The King's Fund, *Experience based co-design, Adapting the approach to your budget*  
[www.kingsfund.org.uk/ebcd/budget.html](http://www.kingsfund.org.uk/ebcd/budget.html)

### Good practice checklist

- Be clear about why you want to gather stories
- Start planning early including consideration of potential barriers and how these will be overcome
- Identify resources required
- Develop project-specific information and consent forms for storytellers
- Decide on recording methods
- Identify potential storytellers
- Gain informed consent
- Practice active listening skills
- Help storytellers to identify key learning points throughout their journey
- Support storytellers to share their experiences
- Ensure contact information is accurate
- Manage storyteller expectation
- Arrange recording in an appropriate setting
- Ensure patient confidentiality and adherence with all relevant legislation and policies as these pertain to the project
- Consider disclosure requirements
- Keep storytellers informed of progress
- If required, edit recordings sensitively
- Feedback to storytellers about impact and say 'thanks'

Further information and sources of support can be found on the Little Things Make a Big Difference website [www.knowledge.scot.nhs.uk/making-a-difference.aspx](http://www.knowledge.scot.nhs.uk/making-a-difference.aspx)

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Further copies of this document are available on request, in audio and large print formats and in community languages. Please call 0141 223 1435.

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