Tools for Improvement

6

1000 LIVES O FYWYDAU

Making patient safety a priority

Learning to use Patient Stories

GIG CYMRU NHS WALES

www.1000livesplus.wales.nhs.uk

Acknowledgements

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1000 Lives Plus is run as a collaborative, involving the National Leadership and Innovation Agency for Healthcare, National Patient Safety Agency, Public Health Wales and the Clinical Governance Support and Development Unit.

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Date of publication

This guide was published in April 2010 and will be reviewed in April 2012. The latest version will always be available online on the programme's website: www.1000livesplus.wales.nhs.uk

The purpose of this guide

This guide has been produced to enable healthcare organisations and their teams to successfully implement a series of interventions to improve the safety and quality of care that their patients receive.

Further 'Tools for Improvement' guides are also available to support you in your improvement work:

- How to use the Extranet
- A Guide to Measuring Mortality
- Improving Clinical Communication using SBAR
- Using Trigger Tools
- Reducing Patient Identification Errors

These are available from the 1000 Lives Plus office, or online at www.1000livesplus.wales.nhs.uk

> Where reference is made to 1000 Lives Plus, this includes the work undertaken as part of the 1000 Lives Campaign and the second phase of this improvement programme – 1000 Lives Plus.
>
> The guide uses examples from the former NHS organisational structures, and where possible this has been acknowledged.

We are grateful to The Health Foundation for their support in the production of this guide.

The Health Foundation
Inspiring Improvement

Making patient safety a priority

The 1000 Lives Campaign has shown what is possible when we are united in pursuit of a single aim: the avoidance of unnecessary harm for the patients we serve. The enthusiasm, energy and commitment of teams to improve patient safety by following a systematic, evidence-based approach has resulted in many examples of demonstrable safety improvement.

However, as we move forward with 1000 Lives Plus, we know that harm and error continue to be a fact of life and that this applies to health systems across the world. We know that much of this harm is avoidable and that we can make changes that reduce the risk of harm occurring. Safety problems can't be solved by using the same kind of thinking that created them in the first place.
To make the changes we need, we must build on our learning and make the following commitments:

- Acknowledge the scope of the problem and make a clear commitment to change systems.
- Recognise that most harm is caused by bad systems and not bad people.
- Acknowledge that improving patient safety requires everyone on the care team to work in partnership with one another and with patients and families.

The national vision for NHS Wales is to create a world-class health service by 2015: one which minimises avoidable death, pain, delays, helplessness and waste. This guide will help you to take a systematic approach and implement practical interventions that can bring that about. The guide is grounded in practical experience and builds on learning from organisations across Wales during the 1000 Lives Campaign and also on the experience of other campaigns and improvement work supported by the Institute for Healthcare Improvement (IHI).

Contents

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Introduction

This guide is based around the collection and use of patient stories, drawing upon the experience of 1000 Lives Plus. The methodology can be applied to the collection of effective stories from all members of society – patients, carers, guardians and members of staff. Everyone has a different, equally valuable perception of their healthcare experience.

Context

In 2006 the Welsh Assembly Government made a clear commitment to improve patient involvement in the planning and improvement of healthcare services, and more generally, to listening and acting on patients experiences of the services.

"To improve the quality of its services and move forward, the NHS needs to give good and reliable information to its users and potential users, to seek their views, learn from their experiences and take action as a result."[1]

Patient experiences have been used in healthcare as a way to identify areas of improvement, and are recognised as a fundamental tool to achieve a patient-centred pathway and to build engagement into improvement methods.

What is a Patient Story?

1000 Lives Plus defines the term 'patient stories' as the experience of a range of potential storytellers, communicating for different reasons with a range of different audiences.

Stories told by individuals from their own perspectives are of particular interest, including:

- A patient or someone close to them who has experienced excellent care or improvement in services.
- Someone who has had an unsatisfactory experience of healthcare, including an experience of physical or emotional harm.
- A member of staff who has worked as part of a team working to implement patient service improvements.
- Anyone who wants to share ideas about good practice or new research findings.

The idea is to gain an understanding of the healthcare experience of the storyteller; what was good, what was bad and what would make the experience more positive.

An individual story is not in itself representative of all patient experiences. However, each story is valid, as it is the individual's healthcare experience. Collectively, stories can help us build a picture of what it is like as a service-user and how we can improve the service we provide.

Patient stories bring experiences to life and make them accessible to other people. They encourage the NHS to focus on the patient as a whole person rather than just a clinical condition or as an outcome.

Healthcare has the opportunity to shift the "traditional view of the user as a passive recipient of a product or a service to the new view of users as integral to the improvement and innovation process."[2]

Patient Stories and Quality Improvement

Quality improvement depends on frontline staff generating fast improvement cycles in the setting where the work is delivered.

Because of the fast and localised nature of quality improvement work, it suits a variety of different tools to identify and monitor projects.

Patient stories have unique features which make them appropriate in quality improvement projects:

- Stories are subjectively told from the point of view of the narrator and therefore the attention focuses on the individual and not the organisation/condition.
- The narrative structure of the story aligns events (time vs. plot) and help making sense of the experience.
- Stories are non-linear and are made of a complex network of events, actions, relationships and environments.
- Stories have an ethical dimension that reflects society's expectations of "good behaviour".
- Stories are action-oriented and focus on events and actions, and provide insights into what could have happened.
- Stories help bridge the gap between the formal codified space of the organisation (job description, roles, accountability) and the informal unwritten rules and sub-cultures.[3]

Through 1000 Lives Plus, patient stories have been tested by all NHS organisations in Wales to ensure that the patient voice is heard at the most senior level of the organisations. This helps ensure that improvement of services is centered on the needs of its users.

1000 Lives Plus recognises the importance of patient stories as a lever for change by including their use at Board level as part of the Improving Leadership for Quality content area.

Using specific patient stories to complement quantitative data reports can be a powerful way of increasing focus and engagement with quality and safety issues. Using patient stories in formal meetings can be challenging and a progressive approach is promoted by 1000 Lives Plus, based on the IHI primer for the Use of Patient Stories.[4] This allows organisations to become familiar with using stories in different formats and using positive stories before engaging with more challenging stories concerning patient harm.

There are now examples of the effective use of stories of harm in Board level committee meetings. For the approach to be effective, it is important that links are made between the story and organisational safety risks and improvement priorities.

> ***Case study***
> Patient stories are well established as the first standing agenda item in Quality and Safety Committee meetings in Cwm Taf Health Board. The Committee Chair found them to be an invaluable tool for engaging all Committee members in discussion and for focusing attention on quality and safety.

We have identified two dimensions to patient stories:

1. The practical and technical aspect of patient stories (how, where, by whom and when stories will be collected and stored).
2. How patient stories can be used.

References

[1] *Healthcare Quality Improvement Plan, Welsh Assembly Government, November 2006, page 17.*

[2] *P. Bates, G. Robert. Experience-based design: from designing the system around the patient to co-designing services with the patient. Quality Safety Health Care 2006.*

[3] *T. Greenhalgh, J. Russell, D. Swinglehurst. Narrative methods in quality improvement research. Journal of Clinical Nursing, 12, 422- 43*

[4] *www.ihi.org*

1.The practical and technical aspect of Patient Stories

‘How to’ (RCN/Discovery Interviews style)

A number of approaches to collect and use patient experiences/stories already exist in Wales, such as the Royal College of Nursing (RCN) Clinical Leadership approach, the Discovery Interviews style used by the South East Cardiac Wales Network.

This guide describes an approach which is based on the RCN/Discovery Interview models, but has been generalised and simplified to ensure readers can adapt and apply the approach to their own needs.

The following page provides a quick and simple flow chart of the stages required for the collection of patient stories as a quality improvement tool.

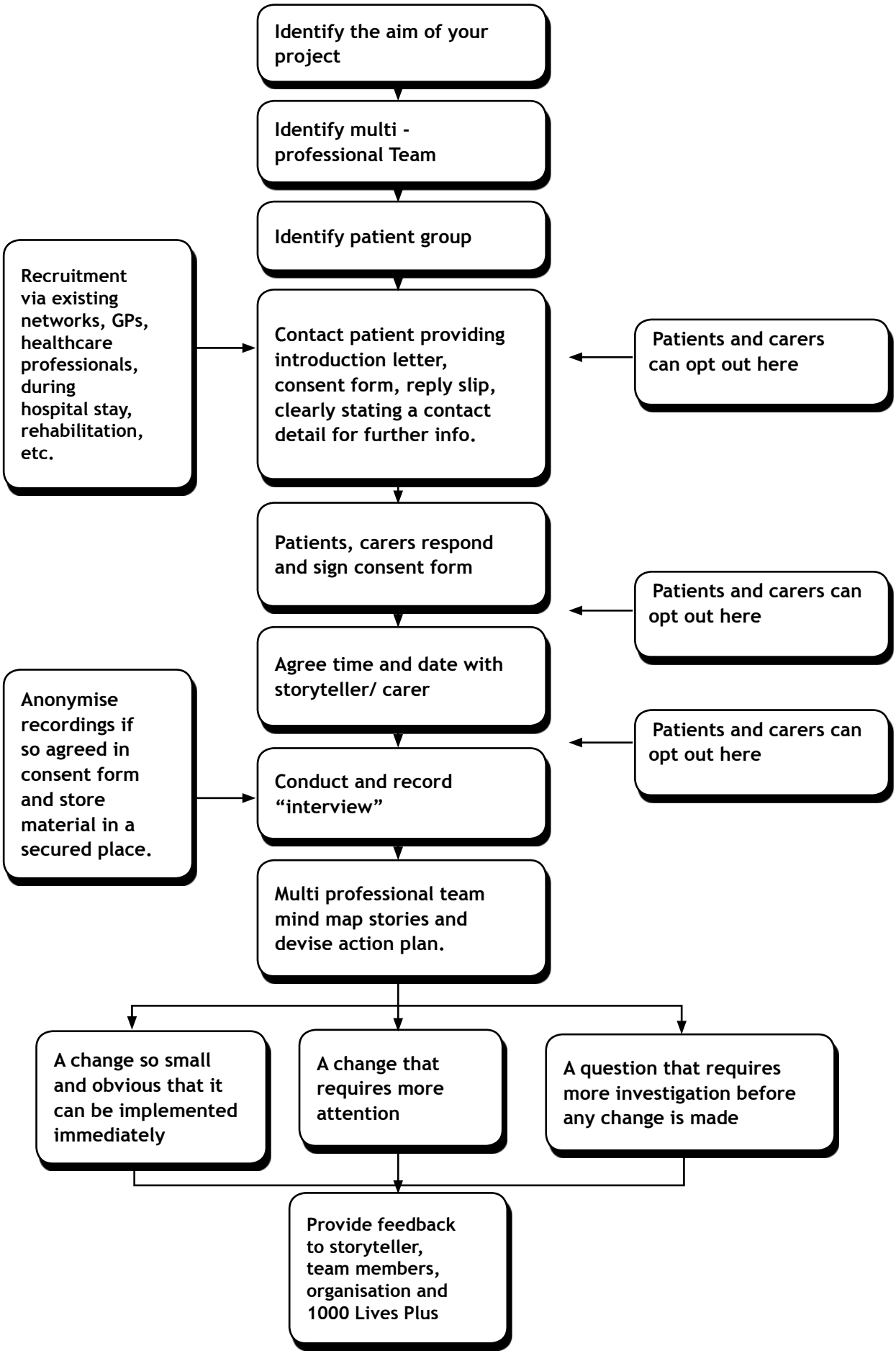
You will need to be aware of the road ahead before you set off on your improvement journey.

The processes and issues

Following the ‘Model for Improvement’ methodology you should start with a small test of change. (See the ‘How to Improve’ Guide for more information.)

The following pages are designed to provide you with a general understanding of the processes and issues related to collecting and using patient stories, but this should not be a substitute for attending specific training in this field.

Stages for the collection and use of patient stories



1. Identify the aim of your project

It is essential to identify why you wish to take patient stories before you go any further.

Patient stories are one of the most effective approaches to gain a thorough understanding of patient experience; however, they may not be suitable for all situations.

It is valuable to consider other approaches for gathering information relating to patient experience. Questionnaires, semi-structured interviews, focus groups, and diaries each have their merits and may be more appropriate in certain situations.

Your knowledge and understanding of the service will help you identify the aim of your project. This, in turn, will help you choose the best tool to achieve it. You may want to explore patient experience of your service in very general terms or you may wish to probe more deeply into some specific aspect of the service.

2. Identify the multi-professional team

Taking stories is not a new concept and it does not need be a complex process. Society requires us to exchange stories everyday. The difference is how we create the opportunities to listen to patients telling us their stories and what we do with the information received.

It is strongly recommended that patient stories are developed and managed as a team approach.

From the beginning, managers and executive leads should be aware of what you are doing and why. Senior support will help you develop your team, and is essential to successfully implement any service improvement identified through the stories you collect.

When possible, bring together a team of people from a variety of disciplines as different people will hear different things from the same story. This will help you to get the most out of the stories taken.

Too often the collection of stories has been solely associated with the nursing profession, but everyone involved in providing care for patients should be considered as a possible member of your team.

Students should also be considered as an addition to the team. If you do engage students, you must ensure that the ownership and responsibility of the material collected is clearly placed with the organisation and not the student.

A multi-professional team approach will not only allow a fresh and varied look at the material collected, but will also support the implementation of changes and help ensure an ethical approach is followed at all times.

It is recommended that the person/s taking the story should have no involvement in providing care for the patient. Patients may fear possible ‘retribution’ if telling their story to a staff member involved in their care, especially if their experience is not as positive as it could have been.

One way of doing this is by 'buddying' up with a different service area and taking stories for each other. This also provides a slightly more objective perspective which will also help to generate discussion and thinking.

> ***Case study***
> A primary care team in Abertawe Bro Morgannwg University Health Board decided to collect patient stories to identify patient perceptions of anticoagulant management with a view to implementing some changes (from Hospital to community managed at GP level). The interviews were jointly collected and analysed by a Pharmacist and the Head of Quality and Patient Safety, whilst the patients were identified and contacted by their GP. The team found that a multi-disciplinary team approach was extremely helpful to identify themes from the material collected.

3. Ethical Consent

The ethics question often arises when embarking upon a quality improvement process. Formal ethics committee approval for the gathering of patient stories is not always necessary; however, it is absolutely essential to carry out what you do in an ethical way.

If you are collecting stories for a formal research project (not for service improvement) you must seek formal ethics committee approval. We also recommend that if stories have never been collected in your setting, you seek advice from your local ethics committee.

Your primary consideration should be maintaining an ethical approach. Thoroughly planning your project in advance will help you minimize the risk of unethical behavior. This, combined with attendance at specific training, should ensure your project is conducted ethically.

You should also bear in mind at all times that the story belongs to the patient storyteller.

If you have collected a story for a specific purpose you can not use it in any other way than that specified in the consent form. For this reason, we strongly recommend ensuring that an option allowing further contact is included in the consent form.

Many organisations are developing their own policies on the collection and use of patient stories. There are likely to be examples of consent forms already in use in your organisation. (See Appendix 1 for a sample form.)

Many organisations are also developing a central register of stories collected (along similar lines to clinical audits) and an equipment resource. This will help ensure that stories are conducted in an ethical manner, and that the information gathered through this process is used effectively. The Public and Patients Involvement (PPI) Lead in your organisation is the most likely link to gain access to these recourses.

You may wish to enquire if any stories previously collected could be applicable

and relevant to your project, could you analyse this material instead of collecting new stories?

As previously mentioned, consider including in your consent that you can seek (if necessary) further contact with the patient. You may collect a very powerful story but not have the right consent to be able to use it wider than as a service improvement tool.

To make sure you take stories in an ethical way, you need to:

- Provide the patient with adequate information that is easy to understand.
- Refrain from pressurising the patient into telling their story.
- Be explicit about what will actually happen. For example, be clear about how you will take the story (notes / tape recorder / video) and what will happen to the story afterwards.
- Make sure that you get formal consent from the patient before you start.
- Maintain the patient's confidentiality.
- Respect the patients wish to remain anonymous if that is the case.
- Make sure the patient understands that if you hear something that puts others at risk, you will have to do something further with that information.
- Make sure that your manager / organisation is committed to using the information collected and see the long term benefit of collecting and using patient stories.
- Make sure that the patient feels 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.
- Be able to offer support after the story is taken if needed. Story-telling can be an emotional experience for both the patient and the person taking the story. This could be in the form of access to counseling support. This will not always be necessary but it should be available if needed. The person taking the story may also need support, for example a de-brief if the story collected is particularly distressing.
- Allow the patient to stop at any time.

4. Building skills

Even though we hear and tell stories everyday in our lives, taking patient stories should not be approached without a clear understanding of the process required.

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.

Some people are naturally better than others at taking stories, but it is advisable to try and make sure that whoever is taking the story fully understands the process and has received training.

Many NHS organisations will have a number of people who have been through the Royal College of Nursing (RCN) Clinical Leadership Programme. A key part of this programme is around patient stories and it is valuable to link with these teams.

The South East Wales Cardiac network has also developed training on the use of Discoveries Interviews. A very comprehensive 'How to' Kit is available from their website www.sewcn.wales.nhs.uk

Case study

Cardiff and Vale University Health Board provided a number of patient stories workshops based on the RCN Clinical Leadership Programme methodology for which they have a licence.

Case study

Abertawe Bro Morgannwg University Health Board linked all nurses undertaking the RCN Clinical Leadership programme in 2008/9 to areas of relevance to 1000 Lives Plus. The organisation showcased all 29 stories and subsequent improvement projects.

5. How to identify patients

It is important to ensure that the stories are collected from the correct population to meet the aim of your project. The aim itself will help you identify what type of stories you will need - whether they should be patients, carers or staff stories. In some cases you may need to collect stories from various populations (patients and staff for examples).

> ***Case study***
> Aneurin Bevan Health Board (Caerphilly Locality Office) has started a project looking at the effects of replacing small community hospitals with the new Local General Hospital at Ystrad Fawr. The project will collect and produce stories from both patients and staff.

Existing networks are a great source of patient stories and many secondary care settings hold a number of patients groups which you may be able to tap into if appropriate. Consider approaching your PPI Lead or Hospital Chaplain for more information.

Many primary care settings also benefit from patient and carer groups. Alternatively, Community Health Councils (CHC) and Expert Patients Programme groups (EPP) are also an excellent link to patients willing to tell their stories. GP practices should be able to direct you to their local EPP coordinator.

Advertising your project with posters and information leaflets in public areas can also provide access to willing patients.

Make sure you give patients time to consider whether they wish to give you their story. You should allow at least a week, if possible, between contacting the patient and providing all information regarding the project, and completing the consent form.

> ***Case study***
> The former Conwy and Denbighshire NHS Trust and Local Health Boards organised a public information bus where members of staff visited local supermarkets to engage with local communities to inform them of the 1000 Lives Campaign and to collect stories of patients' experiences of their local healthcare.
>
> The event was a success in engaging the local community but it did not prove to be effective in collecting stories. Members of the public were happy to have informal discussions with staff, but not to formally provide their stories. Staff also relied on people contacting staff after the event rather than the other way round, which may be the ideal option for future events.
>
> Organisers acknowledged that patients needed previous knowledge and understanding of the project and its processes to allow them to confidently provide their stories.

6. When and where to collect the story

Ideally you will collect the story when the patient is no longer in receipt of care, as the patient will find it very difficult to express any negative comments if they think there may be consequences in doing so.

However, this is not always possible, especially when the patient is receiving long-term care. In this situation, you need to be conscious of the patient's need to feel safe when telling their story and the need for the experience to be relatively fresh in the storyteller's mind to ensure an accurate account.

You must respect that each individual will require different time frames and in the case of chronic or on going conditions / treatments, you must be very flexible to ensure the needs and welfare of the patient are respected.

Consideration needs to be taken during the planning stage of where the story will be collected.

Your organisation's Lone Worker Policy will need to be taken into account to ensure the safety of staff.

In addition, you will need to consider the needs of the storyteller. A neutral setting may be preferred rather than visiting the patient at home or inviting them back to the healthcare setting you are investigating.

If you are visiting a patient in their home this may cause some distress to the storyteller as they may feel their house needs to be well-presented.

When looking at secondary care settings it may not always be appropriate to invite patients back to the ward where their care was provided. A lack of private spaces may be one obstacle, but also the patient may not feel comfortable revisiting the environment associated with their story.

> ***Case study***
> Velindre NHS Trust collected patient stories from cancer patients, and in some cases these were collected up to three years after the patient's treatment. However, they also collected stories from relatives just a few weeks after the patient had lost their battle with cancer.
>
> Stories were collected from cancer survivors out of working hours to accommodate the needs of the patient. The hospital was chosen as the location to take the stories but patients requested that the interviews were held away from the wards, so managerial offices were used. The organisation worked very closely with the storyteller in the planning stage to ensure the needs of everyone involved were respected.

7. How to collect the story

Audio recording a story allows you to concentrate on the discussion when you are with the patient, instead of worrying about keeping accurate notes of what is being said. It enables you to re-listen to the story with a colleague who may hear different things to you.

Audio recording of stories allows you to retain the patient's anonymity. Assuming you have appropriate consent, you can use quotes or clips from the stories in other situations without the need to say who or where they came from.

Audio recording equipment can be found in many healthcare settings or can be acquired at very little cost. Hospital Radio Stations may also be a possible source for recording facilities.

Filming the story opens up a host of potential uses but you need to be sure that the consent you take covers where and why it will be shown. This approach will require a lot more planning and resources. It may be that you decide to take stories initially via another mechanism and film specific ones afterwards.

Case study

Hywel Dda Local Health Board developed a short film depicting an actor re-telling the story of a patient who had received poor care during their hospital stay.

The video was created as a training tool for staff to address the impact of poor care and also for training in the collection and use of Patient Stories. The clip was professionally created using the transcript of the original patient story, which was taken for service improvement purposes.

Case study

Hywel Dda Local Health Board developed a training tool by working very closely with the relative of a patient who died as a result of medical errors. A relative's story was audio recorded and it was decided that because of the number of issues the story raised, the story should not be developed into a digital story or filmed.

The organisation fragmented the audio recording into specific topics and built a training session around the whole story.

Digital stories are becoming very popular and there is growing interest amongst the service. Our experience is that this can be a very powerful tool, but it does require some technical knowledge and specialist software.

Non-NHS companies are available to develop Digital Stories, and some NHS organisations are currently looking at developing in-house skills.

We recommend audio recording each story to its best possible recording quality as this, and adequate consent, are the basic requirements for completing a digital story.

Because of the cost generally associated with digital stories, we recommend embedding the use of patient stories as a service improvement tool before embarking in this field, unless the organisation has a specific need to develop stories in this format (e.g. to present to the Board).

If you feel unable to use audio-recording or filming, discuss in your team the opportunities that already exist for patients to provide feedback on their experiences within day-to-day practice. It may be that you can collect valuable information through these, but bear in mind that you may not get the full picture.

Whatever approach you take to collecting your stories you need to make sure you have fully explained to the patient what will happen and what you will do with the information afterwards.

It is recommended that you familiarise yourself with the equipment before attempting to take your story to ensure smooth running of the operation.

Once the material is analysed you must store the information in a secure place according to your consent. For example, if your consent specifically states that all material will be anonymised, then you must do so from the moment the material is collected.

Apply the Model for Improvement to this exercise and test this approach on one patient; do not attempt to collect too much material too quickly. Between three and six stories will be enough material for the majority of projects.

8. Additional considerations when collecting a story

It is important to be aware of your personal reactions and how they can influence the storyteller. In the same way that it is natural to feel proud when someone praises you, it is also natural to feel defensive when someone makes a criticism. For example, if you look perplexed at something the patient says, you may encourage / discourage them to pursue that line of thought. However, no reaction would appear strange. You need to maintain a healthy balance of empathy that encourages the story to be told.

When taking a story it is not your role to answer questions or solve any dilemmas. This is why it is important to be clear at the outset about what the process will involve, so that the patient understands why you are there and does not feel disillusioned if unrealistic expectations are not met.

Patients may start the process with a view that everything was rosy and simply want to praise the system. By asking them to help you understand what it was that made them feel good you can encourage them to talk. You may also uncover some things that were not so good – often referred to as ‘small’ issues, but ones that in reality make a huge impact on individual experience. (See Appendix 2 for some suggested prompts you could use during the story collection.)

Patients may raise issues that are of concern to others during their story. You must make them aware through the consent process at the start that if anything is raised which could be of potential harm to others, you will have to take necessary action.

9. Learning from your experience

The RCN and the Discovery Interviews approach how to analyse the material in slightly different ways but both approaches are equally valid.

In this guide we will give a very general overview of the process, but it is strongly recommended that specific training is attended before starting the project.

You must also ensure that your consent allows you to analyse the material according to your needs. If your consent does not cover certain aspects you may need to seek further consent, so do plan your project carefully before setting off.

As previously mentioned, we strongly recommend that you record the stories as this will make it easier to analyse the material collected and pick up the issues as they emerge.

Transcribing the material is in many cases not necessary and, as it is very time consuming, we recommend that you do so only if you are absolutely sure of the benefit this will bring to your project. You may wish to initially make a note of the times of the main quotes and progress according to the steps described below, before committing to transcribing all your material.

The analysis stage should always be undertaken by more than one member of the team, the person that undertook the story does not necessarily have to also analyse its content. If, for example, your material was collected by students during their placement, they will not necessarily be involved in analysing the contents as they may have moved to a different placement by then.

The benefit of setting up a multi-disciplinary team becomes apparent at this stage. Involving people with different backgrounds and expertise will enable a varied look to your material.

Generally, teams analyse the material together but this may not always be possible. As long as the same methodology is applied it can be done independently. Each member's findings can be merged and any conflicting issues discussed as a team.

To analyse the material you should play-back each story and 'mind map' the contents.

- Start by putting the identifiable code of the patient at the centre of a page.
- Begin mapping the story from the top right corner and work outwards and clockwise as different incidents or episodes emerge. You should write down just key words at this stage, circling them to ensure they are clearly visible.
- After this, listen to the story again, adding more details to the key words you plotted initially, this time the notes will show as ramifications of the key words you encircled previously.
- This process should be repeated until the map represents the meaning of the story.

An example of a ‘mind map’ from the RCN Clinical Leadership Programme can be found on the following page.

Each story should be ‘mind mapped’ and each team member should execute their individual exercise. If time constraints will not allow each team member to ‘mind map’ every story, you can share the stories between all team members.

When all stories have been mind mapped the team can come together and identify any common themes that have emerged from the stories collected.

The themes help you identify areas for quality improvement and indicators of good practice. It is important to do both of these, and not to simply focus on any negatives.

It is imperative that you do something with the story you have collected, for example make sure you provide any positive feedback back to the service. You do not have to implement every change that may be raised by the story. Some issues may be impossible to solve, but some may be extremely simple and could be implemented at no cost and immediately. Use the themes to create your own action plan.

Once you have developed your action plan you should provide the storyteller and the organisation with some feedback on what changes are planned and if possible keep them updated on progress.

Case study

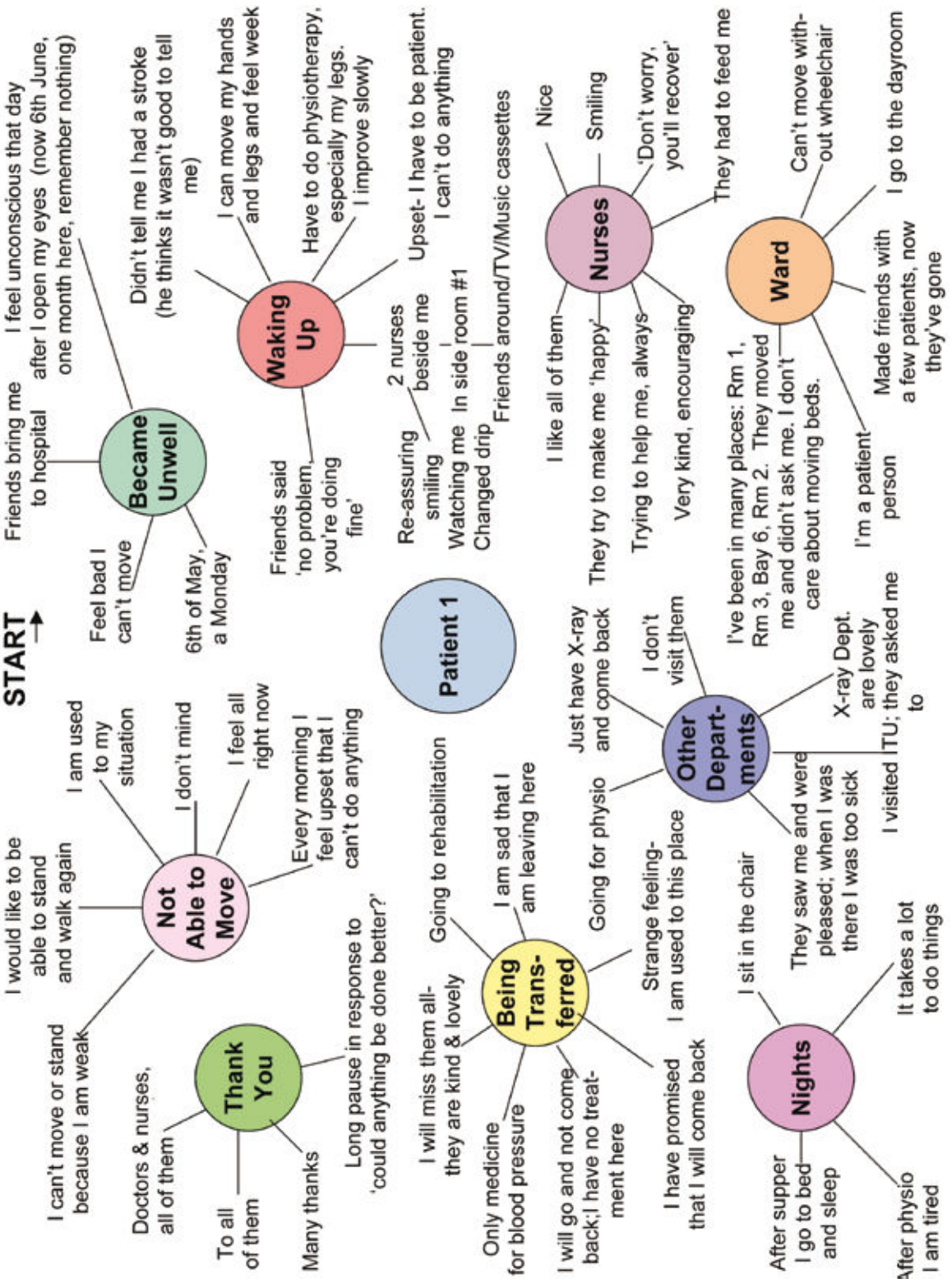
Following the story of a patient who received a negative experience in an Acute Medical Unit in Betsi Cadwaladr University Health Board (Central), the team worked passionately to improve their service.

When the same patient was unfortunately re-admitted to the same unit two years later, her experience was completely different. The patient provided a second story praising the improvement work that had been implemented and embedded in the unit.

Providing the positive feedback has inspired the staff to ensure the level of care is maintained and the improvement work remains high on the agenda.

1000 Lives Plus is also interested in hearing about your work and experience. Remember to include in your consent the possibility of sharing the stories with other (non-commercial) organisations, like 1000 Lives Plus.

Example of a Patient Story Mind Map (from Royal College of Nursing)



2. How patient stories can be used

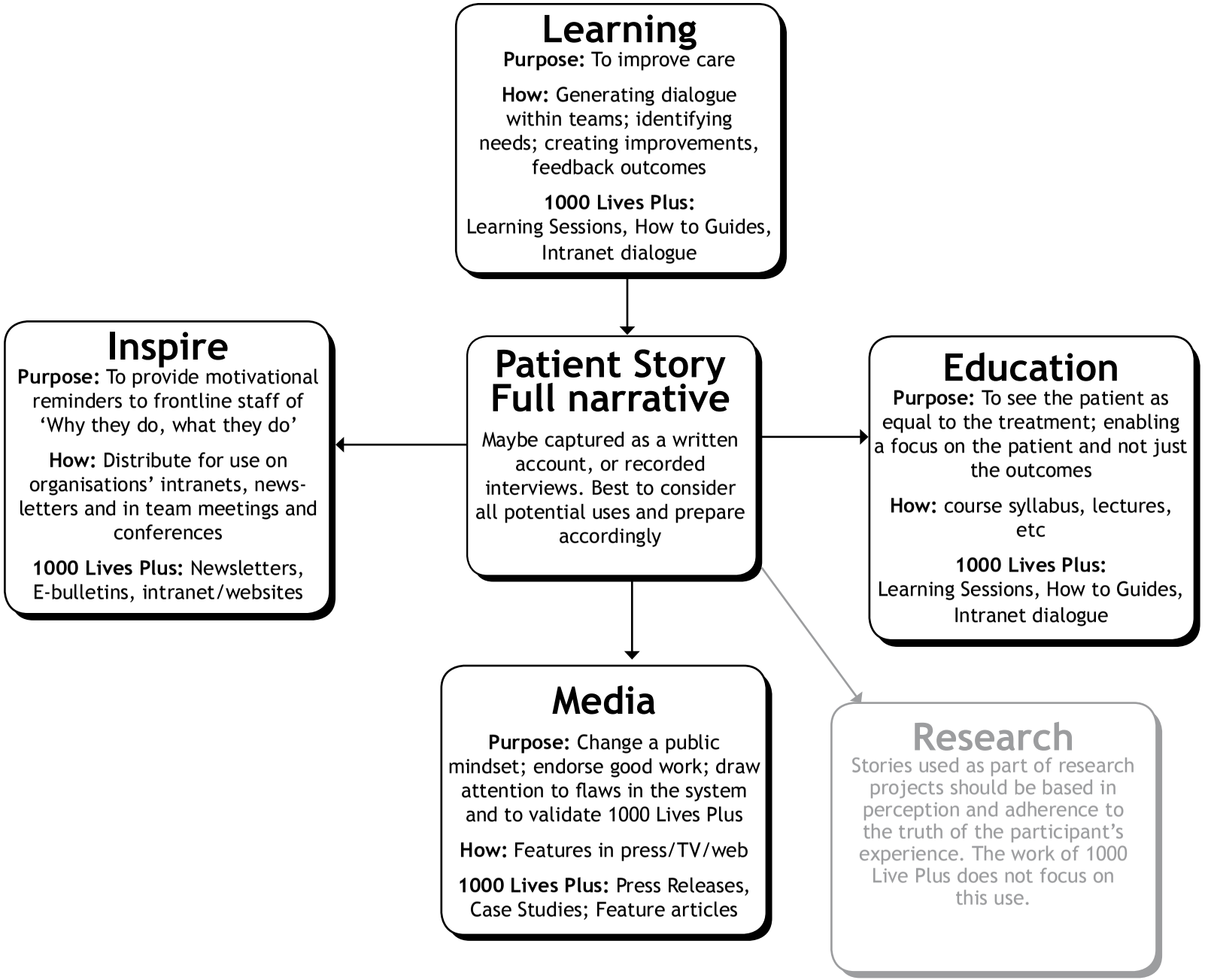
Stories have the potential to inspire us to make successful changes, to educate our current and future workforce, to support learning about what works well and to promote excellence within the media

The Model: 1 Story – 4 Applications

1000 Lives Plus has developed a patient stories framework to help organisations make the most of the invaluable information collected through patient stories.

The following diagram shows four possible uses identified and encouraged by 1000 Lives Plus. Stories can also be used as an academic research methodology, but readers must be aware that a very different approach than the one described in these pages should be applied in this case.

1 Story - 4 Applications: Collecting stories for 1000 Lives Plus



Patient stories to inspire

Listening to a patient telling their story in their own words is a powerful experience. It reminds us of why we do what we do in the NHS and it has the power to capture both our hearts and minds.

We live and work in the real world with all its competing challenges and frustrating set-backs. Sometimes it can be difficult to remember patients are at the core of what we do and the real reason the NHS is in existence.

Patient stories can inspire us to look at how we can do things differently which can help us make a positive difference to people's lives.

Inspirational stories have been successfully used by many organisations using internal communication avenues such as e-bulletins and intranet sites, but also in team meetings and presentations.

Case study

Aneurin Bevan Health Board (Caerphilly Locality Office) ran an event for staff providing diabetes care, and as part of that day they wanted to show some patient stories.

Through the Diabetes Expert Patient Programme for Caerphilly Locality three patients agreed to tell their stories and have their stories shared at the event.

At the event a recording of the stories read by someone else was used in combination with slides. This helped the audience to remember the purpose of their roles and the focus of the day.

Patient stories to educate

Patient stories can provide an opportunity to shape the healthcare of the future. If we embrace the fundamental premise that patients are equal partners in healthcare, we can work with them to educate our current and future workforce.

By educating our workforce we can equip people with the skills required to work together with patients, to involve them in decisions that affect their lives and have positive outcomes in healthcare.

1000 Lives Plus is encouraging organisations to support students in the collection of patient stories as part of their work placements, linking students with improvement projects underway.

Case study

A primary and secondary care team at Betsi Cadwaladr University Health Board has teamed up with a patient representative.

The patient is now part of a training team visiting many community pharmacists and GP practices explaining what is like to live with a Chronic Heart Failure (CHF) condition.

The training is intended to help improve the management of CHF patients and increase awareness within the community based healthcare professionals.

Patient stories to help us learn and improve

One of the most powerful elements in listening to a story is the profound impact it has on the listener. The information gathered from the story is in itself an important element of learning. However, there is another element demonstrated through the change of heart that it encourages in the listener.

Patient Stories can be a powerful tool in the application of the Model for Improvement methodology, by helping spread successful changes. Patient and staff stories are successfully used as part of 1000 Lives Plus to facilitate the spread of clinical interventions, helping enthusiastic staff members to engage with more sceptical staff.

> ***Case study***
> The Welsh Ambulance Service NHS Trust has successfully implemented training for the identification and treatment of laryngectomy patients, due to the impact of one patient story. A new multi-organisationsal system is also being tested, which aims at identifying such patients to ensure correct transport is allocated.

Patient stories for the media

It is a modern phenomenon that small minorities of stories with negative connotations attract media headlines and have a powerful influence over public opinion.

Patient stories provide an opportunity to start shifting this balance. They can be promoted in both local and national media to raise public awareness about what is good and where improvements have been made.

1000 Lives Plus supports organisations in strengthening relations with their local media to provide communities with a better understanding of the healthcare system. Stories have been a successful tool in bringing the NHS closer to their local communities.

> ***Case study***
> Abertawe Bro Morgannwg University Health Board acute sector developed a patient story as part of celebrating one year without pressure ulcers celebrations in Anglesey ward, at Morriston Hospital.
>
> The Health Board's Communications Officer purchased a low budget hand-held video camera to record the story of a patient representative who had previously experienced a pressure ulcer.
>
> The patient also agreed to collaborate with the Communciations Officer to provide a short interview on the same subject which was broadcasted in the national news.

Appendices

Appendix 1 Patient Story Consent Form

Organisation: Project:

Department: Reference Code:

This form is to give my agreement as a patient to the telling of my experience of _____ in a patient story.

I understand my story will be digitally recorded and will be kept indefinitely. Some sections or quotes may be used by _____Health Board/Trust for the following purposes.

☐ Improving our service ☐ Staff Newsletter

☐ Presentations ☐ Reports

☐ Website ☐ Leaflets / Brochures/ Posters

I understand I can change my mind after telling my story at any time without giving a reason, and this will not affect in any way any future care that I or my relatives may need.

Sometimes patient stories are shared and the first name and age of the patient are given. Please tick one of the options below:

☐ I am willing to have my first name and age known.

☐ I am not willing to have my first name and age known.

I understand that _____ Health Board/Trust might need to contact me again about this story and I am happy for them to do so. ☐

I understand that my story might be shared with other NHS organisations and I am happy for this to happen. ☐

I agree to tell my story about my experience as a patient who received healthcare services. The purpose has been fully explained to me and I am happy to tell my story and for it to be used for the purposes above.

Patient's Signature: _____ Date:_____

Name (PRINT):_____ Date of Birth:_____

Signature of person taking the story:_____ Date:_____

Name (PRINT):_____ Job Title:_____

Add contact details of the person taking the story
(Name, work base, email address and phone number)

Appendix 2 Useful prompts

Taken from the Royal College of Nursing Clinical Leadership Programme:

- Tell me about when you became unwell...
- Tell me about when you came into hospital...
- What do you remember most?
- What was your care like?
- Do you have a significant memory of your care?
- Was there anything that surprised/worried/pleased you?
- Tell me more about....
- You said this [ ], can you help me understand that a bit better please?
- How did that make you feel?

1000 LIVES O FYWYDAU

Improving care, delivering quality

If we can improve care for **one person**,
then we can do it for **ten**.

If we can do it for ten,
then we can do it for a **100**.

If we can do it for a 100,
we can do it for a **1000**.

And if we can do it for a 1000,
we can do it for **everyone in Wales.**

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