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Welsh Health Specialised
Services Committee (WHSSC)

PATIENT EXPERIENCE AND ENGAGEMENT FRAMEWORK WHSSC



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Pivotal for WHSSC to the success and delivery of the Commissioning Assurance Framework is ensuring that patients are put at the centre of Commissioned services. They are integral in monitoring the quality of care and in the development and improvement of services for the future. The Patient and Public engagement document forms part of the suite of documents to support and enable the delivery of the Commissioning Assurance Framework.

The main aims of WHSSC's patient and public engagement are summarised as follows:

- Understand the patient's expectation of a particular service
- Put things right if the patient experience was not as expected or planned
- Understand differences in patient experience between locations and types of treatment
- Make changes where needed and highlight areas where changes have improved care
- Monitor the outcomes and benefits of treatment in terms of a person's physical, mental and social wellbeing
- Inform WHSSC how a service or particular treatment is being provided
- Plan future service provision
- Understand the delivery of a value based health care approach
- The patients role in the decision making about their care

Good experience of care, treatment and support is an essential part of an excellent health and social care service. This alongside clinical effectiveness and a culture of safety puts the patient first and gives patient experience the highest priority.

A person's experience starts from their very first contact with the health and care system, right through to their last, which may be years after their first treatment, and may include end-of-life care. Providing compassionate care good emotional support and involving patients in decision-making enables positive patient experience (NHS Improvement, 2018).

There is an expectation that commissioned providers can demonstrate an open and transparent organisational culture which will have a positive impact on staff and patients alike and support quality improvement and innovation programmes. Factors such as leadership and culture underpin an ability to improve patient experience where staff are proud of their organisation as a place to work



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Patient experience is enhanced when staff ensure there is time for patients to ask questions, when people using the services are treated as individuals and their specific emotional, cultural and social needs are considered (NHS Improvement, 2018).

The drive towards closer integration of health and social services with improved public engagement is reflected in the aims of A Healthier Wales (2019). This sets out the goal of ensuring citizens are placed at the heart of a whole system approach to health and social care services and stresses the importance of listening to all voices through continual engagement. The Health and Social Care (Quality and Engagement) (Wales) Act 2020 will strengthen the voice of citizens, by replacing Community Health Councils with a new All Wales Citizen Voice. The Citizen's voice will further strengthen

- An effective mechanism to have Citizen's views heard
- Ensure Citizens are supported when making a complaint in relation to their care
- Use the user service experience to drive forward improvement including the involvement and consultation of the users in service delivery changes.

The new organisation will be established as a public body and structured to enable it to perform its functions at a national regional and local level. A Code of Practice will also be published by Welsh Government for the Citizens Voice body when seeking the views of individuals. Working in partnership with Citizen's voice will be key in the planning of new services and the monitoring of commissioned services. As a member of the Quality Patient Safety Committee they will also have an overview and ensure that the voice of the patient is at the centre of decision making.

In addition the Well-being of Future Generations Act (2015) will require public bodies in Wales to think about the long-term impact of their decisions, to work better with people, communities and each other.

Every contact with a patient is an opportunity to support someone to better maintain or improve their own health and wellbeing, which will often mean looking beyond their immediate symptoms or needs. Prudent Healthcare commits to ensuring decisions and choices are taken forward hand in hand with those receiving services and this extends to how system supports lifestyle

and wellbeing choices. This will be an increasingly important part of putting the citizen at the heart of a whole system approach.

Ensuring representation from all stakeholders when planning and evaluating services is key for WHSSC. Activities should be inclusive and equal opportunity given to fully participate in patient and public engagement activities in a manner which reflects and supports this.

The WHSSC Commission Teams and Networks will ensure patients and public are engaged and involved through a number of forums. These will include representation and participation on the Individual Patient funding panel, the Clinical Impact Assessment process, Independent members on the Quality Patient safety forums and all project boards.

Some examples of direct Engagement may involve

- Meeting with patients and obtaining patient and carer stories
- Including representation on WHSSC working groups and committees
- Undertaking patient surveys and questionnaires
- Encouraging patient's public to contact WHSSC in writing, in person or through website
- Investigating, responding and reporting of complaints
- Establishing focus groups and/or patient panels on specific topics
- Inviting patient representatives to service improvement and innovation workshops

Indirect Engagement may involve

- Undertaking visits to hospitals and Specialised units where treatments are funded by WHSSC and speaking to the staff and reviewing the environment
- Internal reporting of actual and potential issues with a particular service
- Collating compliments and areas of best practice
- Keeping updated on current media interests in UK wide patient feedback and NHS developments
- Requesting clinical updates on patients post treatment
- Maintaining a website that is easy to use and gain access to important information.
- Undertaking regular audits and reviews of services funded by WHSSC including presentations on Quality Improvement initiatives and development of these



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- Monitoring patient feedback from provider services, through Quality indicators and through data collected on the Once for Wales site.
- Utilizing 3rd party surveys.

The feedback may be classified into the following types:

- 1) **Patient outcomes** – What was the patient’s (and family) experience of the service and to what extent were their expectations met or not met.
- 2) **Process data** – Tells us about the way the services WHSSC funds are delivered
- 3) **Outcome data** – Demonstrates what difference the service has made to the patient and if this was within a prudent model of care.
- 4) **Impact data** – Relates more to the longer-term effects once patients have had their treatment
- 5) **Clinical outcomes** – How the treatment or care impacted on a person’s physical, mental and social wellbeing.

Patient feedback should be considered along with other sources, including complaints and compliments. Collecting feedback from a variety of sources is the best way of identifying and learning lessons from areas where improvements are required and highlighting areas of best practice. The establishment and embedding of the Once for Wales reporting tool into Welsh Health Boards may further support and enhance the development of feedback.

Obtaining balanced feedback

The following table sets out a range of well tested and recognised methods which can be used to provide a balanced view of a patient experience.

WHSSC and the respective commissioning teams will adopt the approaches and embed them into practice to ensure patient experience is captured using multiple methods.



"Real Time"	"Retrospective"
<p>Short surveys are used to obtain views on key patient experience indicators whilst patients, carers and service users are receiving a WHSSC funded service e.g. home care delivery of specialist drugs Or after discharge e.g. cardiac surgery</p> <p>Limitations May be subject to bias, not related to longer term outcomes</p>	<p>Surveys post discharge or any clinical encounter in any setting can provide in depth feedback of a service users experience. Feedback can also be incorporated into quality-of-life measures and Patient Reported Outcome/Experience Measures to inform future planning of services and treatments</p> <p>Limitations Low response rates, reflect average experience not the finite detail of were highs and lows</p>
"Proactive/Reactive"	"Balancing"
<p>Provide opportunities for all service users/families/carers to provide feedback. Includes questionnaires, audit days, Lay representatives on committees and patient groups, online surveys, contact details publicised on web, etc</p> <p>Limitations Recognising where to target surveys and feedback</p>	<p>Evaluate feedback in relation to other sources such as: Concerns and complaints Compliments Clinical incidents Patient stories Patient groups Third party surveys</p> <p>Limitations Small numbers, potential respondent bias</p>

Patient Reported Outcome measures (PREMS) and Patient Experience Measures (PROMS) are frequently used in the NHS to assess the quality of care delivered. Information about a patient’s health and quality of life **before** they receive treatment and about their health and the effectiveness **after** they have received treatment can be used to measure and improve the quality of care, evaluate the specific outcomes of treatments and inform future decisions about how care is planned and delivered in the future.

PROMs are a means of collecting information on the effectiveness of services, care and treatment delivered to individuals as perceived by the individuals themselves. They measure the impact of clinical interventions such as did patient’s physical and/or mental condition improve and if so by how much?

PROMs examples are Quality of Life, Measurement of symptoms e.g. pain, functional ability, distress.

Patient Reported Experience Measures (**PREMs**) gather a patients' objective experience after treatment and aim to remove the subjectivity around the experience of care by focusing on specific aspects of the process of care e.g. were you seen on time?

The feedback received via these questionnaires informs the following areas of Quality:

- **Effectiveness of care** – Does the treatment reduce symptoms, improve function and improve quality of life? (PROMs)
- **Safety** – Does the treatment cause harm or have complications? (PROMs)
- **Experience of care** – What do patients think of the process of care, where they treated with dignity, kept informed, had trust in staff, cleanliness of the environment and timeliness of care? (PREMs)

Services may adapt questionnaire such as PROMS and PREMS to specifically analyse and support patient outcomes and feedback to facilitate effectiveness improve decision making and service improvement further enabling the delivery of a prudent health care system. The Value Based Health care team in Wales are working across Health Boards and with Digital Health and Care in Wales to support a coordinated approach to the development and standardisation of PREMS and PROMS for certain conditions. WHSSC will support and work with the team to facilitate the utilisation of these within specialised services in Wales. WHSSC will also continue to work with the Quality Improvement team in NHS England to gain patient feedback through digital platforms such as the Quality Surveillance Information System.

All patient information will be anonymised. The results of data collection and analysis will be shared as widely as possible to enable closer working, improved communication and patient experience. This will facilitate and support Consultation and Engagement across the NHS to reduce duplication and will support and improve standards of clinical practice.

Patient and public experience of the commissioned services is perhaps the most valuable information that can be captured and incorporated into the



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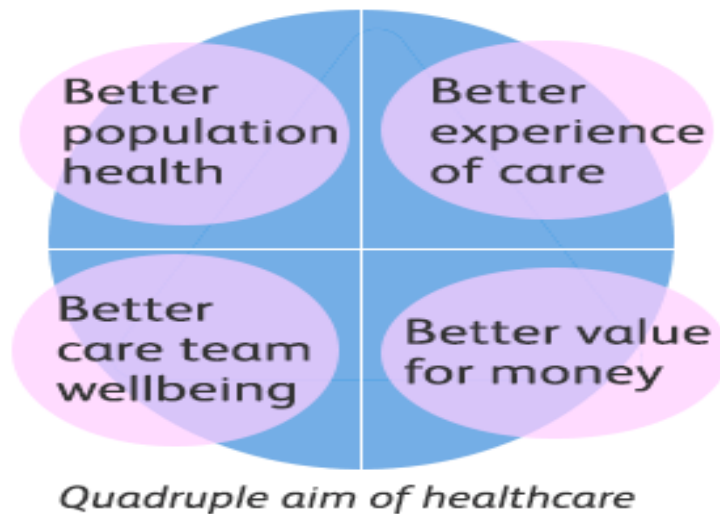
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evaluation of service provision across WHSSC. Measuring what matters to people can be used to establish which services and treatments work well and which ones need to be improved. This information will enable a picture to be built of how it feels to receive care from a particular service or provider and will support and identify best new models of health and social care.

It is critical that the information is gathered in a systematic way and “triangulated” i.e. used along with other related information such as clinical outcomes to:

- promote best practice
- empower citizens to make the best choices regarding treatments available
- reduce variability and treatment across Wales
- support service re design to achieve better clinical outcomes
- provide a measure to determine clinical and cost effectiveness of treatments and services linking to prudent health care

This will further support the Quadruple aim of improved population health and well-being (WG 2019)



Analysis of the information collated

The Commissioning Teams will be central to agreeing a work-plan of patient experience and outcomes required and will work with the relevant providers in collecting the data. Any relevant patient data and the collection of

Patient and public feedback, patient stories, reports from contracted health care providers or third party surveys will be analysed by the quality team and fed into the commissioning team.

The data will be cross referenced to mirror the Health & Care Standards (WG 2016) and incorporated into the commissioning team reports for Quality Patient Safety Committee or into a separate report as deemed applicable.

Shared decision making and co-production between provider and commissioner is crucial in capturing and reporting the data. Shared decision-making is 'an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve preferences' in order to design person-centred care. (Elwyn et al., 2012 cited in Public Engagement and a Healthier Wales, 2020)

Engagement is the active participation of members of the public, communities, customers or stakeholder in service planning, delivery and evaluation. Effective public engagement leads to decisions, delivery and evaluation of services that have been shaped by the relevant people and communities.

Reporting and Acting on Findings

It may not be possible to act on every view expressed but the principles of this framework form a foundation and a driving force to support WHSSC being open and transparent when explaining why and how decisions are made and specialist services are delivered for the people of Wales.

Evaluation will be built into all engagement activities to allow us to not only monitor patient experience but enable us to share and apply any 'lessons learnt'. Equal value will be placed on collecting numerical (quantitative) and narrative (qualitative) information captured as both will provide evidence that the framework is achieving its objective.

Process for reporting feedback

The findings from all of the patient experience work from internal and external sources will be reported through the commissioning team's reports to Quality Patient Safety Committee and included in the performance report. Individual targeted reports will be collated where applicable and a patient story presented to the Joint Committee and Quality Patient Safety Committee to support ongoing discussions as appropriate.



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Conclusion

Patient and Public Engagement are essential to enabling supporting and continuously developing and embedding the Quality agenda throughout commissioned services. WHSSC will ensure that the patient voice and experience is central to discussions and decisions made and the Citizens Voice has been considered throughout.



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Experience and Engagement Framework

