Special Quality, Safety & Experience Committee

Tue 11 October 2022, 09:00 - 12:00

MS Teams

Agenda

09:00 - 09:04
4 min

1. Welcome & Introductions

Susan Elsmore

09:04 - 09:06
2 min

2. Apologies for Absence

Susan Elsmore

09:06 - 09:08
2 min

3. Declarations of Interest

Susan Elsmore

09:08 - 09:10
2 min

4. Chair's Action taken since the last meeting

Susan Elsmore

09:10 - 10:10
60 min

5. Thematic Reviews

Jason Roberts / Meriel Jenney

Maternity / Neonatal – Claire Rowntree/ Andy Jones - *15 minutes*

Emergency Department – Aled Roberts/Jane Murphy – *15 minutes*

Mental Health – Neil Jones/ Mark Doherty - *15 minutes*

Five Harms – David Scott Coombes/ Clare Wade – *15 minutes*

10:10 - 11:20
70 min

6. Quality, Safety and Experience Themes and Trends: August 2021 - August 2022

Angela Hughes

- 6A Special QSE 22 - final.pdf (15 pages)
- 6B Special QSE 22 - Carers annual report.pdf (2 pages)
- 6BB Carers Annual Report 2022 Final.pdf (23 pages)
- 6C Special QSE 22 - Information centre annual report.pdf (2 pages)
- 6CC Annual Report 2022 FV (2).pdf (29 pages)

11:20 - 11:20
0 min

7. Items to bring to the attention of the Board/Committee

Susan Elsmore

11:20 - 11:20
0 min

8. Review of the Meeting

Susan Elsmore

11:20 - 11:20
0 min

9. Date and time of next Meeting:

Susan Elsmore

29 November 2022 at 9.00am

Report Title:	Quality, Safety and Experience legislation, regulation and practice			Agenda item:	6
Meeting:	**QUALITY, SAFETY& EXPERIENCE COMMITTEE – Special Meeting**	Public	✓	Meeting Date:	11/10/22
		Private			
Status	Assurance	✓	Approval	Information	
Lead Executive:	Executive Nurse Director				
Report Author	Assistant Director of Patient Experience				

Background and current situation:

Assessment and Risk Implications (Safety, Financial, Legal, Reputational etc.):
This paper will discuss in more detail the regulatory policies and frameworks:

- Concerns – Complaints
- Referrals to the Public Service Ombudsman for Wales
- Redress and Claims-Clinical Negligence and Personal Injury
- Inquests
- Mortality Reviews and the Medical Examiner
- Patient Safety Incidents
- Covid 19 Investigations
- National Clinical Audits
- Patient Safety Notices and compliance
- Horizon Scanning of future legislation and guidance

Concerns- Complaints

The NHS (Concerns, Complaints and Redress Arrangements) (Wales) Regulations 2011 (hereafter, the 'Regulations') apply to all Welsh NHS bodies, Primary Care providers and independent providers in Wales, providing NHS funded care and was introduced in April 2011. The Regulations set out the process for the management of concerns and is known as Putting Things Right (PTR). The Regulations are supported by detailed guidance on raising a concern.

The process:

- Aims to make it easier for people to raise concerns; to be engaged and supported during the process; to be dealt with openly and honestly; and for bodies to demonstrate learning from when things went wrong or standards needed to improve.
- Introduced a single more integrated approach, bringing together the management of complaints, incidents and claims, based on the principle of 'investigate once, investigate well'

As a Health Board we are committed to listening to people who use our services, resolving their concerns where possible in a proportionate and empathetic manner. We aim to provide an effective and timely process for responding to concerns, which enables the Health Board to improve services based on lessons learnt, with the aim of achieving high quality, compassionate and effective care for all service users, whether in provided or commissioned services.

Redress:

A case moves into Redress if we identify that there is or maybe a qualifying liability i.e. we have identified in breach in our duty of care (care was not reasonable or there was an omission in care) and we know the patient suffered harm because of the breach or we need to investigate further to establish if harm was caused.

We are committed to using the Redress process when appropriate, this enables a timely resolution for those people seeking an apology, remedial treatment and/or financial compensation to the value of £25,000. if we can demonstrate to the WRP that we have followed process, from an investigation and legal context, that we have evidenced the improvements needed to ensure that the learning is used to mitigate the risk of a case like this reoccurring, then we can reclaim the £25,000 settlement and the expert fees incurred. However, the UHB will bear the costs of the claimant's legal fees if they choose to engage a solicitor, which under PTR are capped at £1,920.00.

Redress legal costs significantly save the Health Board. When a matter settles under the Putting Things Right scheme, costs are mostly settled for £1,920. These costs can increase slightly where a matter needs approval in Court, where there is a child or a person who lacks capacity being paid compensation. This could increase costs by an additional £1,752. However, this is still a significant reduction than if the case was settled as a Clinical Negligence claim, potentially savings tens of thousands in costs alone.

The Once for Wales system assists greatly with the reporting of Redress cases, as we have In October 2021, implemented the specific Redress Module, whereby reports will be obtainable to reflect the opening and closing of Redress cases for a specific time period and per Clinical Board.

WRP-Welsh Risk Pool

The Health Board completed the work to comply with the new WRP Guidelines in carrying out a retrospective Learning from Events form for almost 600 Clinical Negligence cases. As a result of the pandemic there was a temporary lapse of the deadline for this work to be completed and for any new triggering cases, although this has reverted back to the 60-day deadline for learning assurance plans to be submitted. This was a substantial additional workload which could have had a significant financial implication if not completed in accordance with the deadlines.

In January 2020, the WRP issued an updated version of their Guidelines with a change of the review of over one million-pound cases, which were previously reviewed by Welsh Government (WG). These would now be reviewed by the WRP at the Learning from Events Panel with WG being invited to attend. This would speed up this part of the process concerning these high value claims. The Health Board would still be required to produce the evidence of learning in the same way as the Health Board cares for many specialist services when sadly litigation occurs the value can be significant.

There has been a change with deferred cases and any cases that have been deferred for payment as further information is required, must be submitted with the additional evidence in an agreed timeframe and failure to do so will mean a permanent deferral and the Health Board would be liable for full costs incurred

During the pandemic, Legal and Risk Services had also reverted to solely working at home, with all case conferences, trials being held electronically which has been successful. During the pandemic there was a temporary reduction of new claims which allowed the Solicitors to focus their attention on finalising a number of cases during the period. In many legal matters, the use of remote meetings, inquests and trials has continued.

It is anticipated that there will be an emerging theme of new claims arising from the period of Covid-19 cases. The Health Board is monitoring this situation and has developed records of key documents that relate to this period, to assist swift investigation being conducted.

Internal Audit

The review was undertaken with the objective of the audit being, to provide assurance to the Health Board's Audit and Risk Committee that the correct process is being followed and that claims are accurate. The purpose of the review was to provide assurance to the Audit and Risk Committee, that the Claims Reimbursement Process follows the Welsh Risk Pool Standard.

RATING	INDICATOR	DEFINITION
Substantial Assurance		The Board can take **substantial assurance** that arrangements to secure governance, risk management and internal control, within those areas under review, are suitably designed and applied effectively. Few matters require attention and are compliance or advisory in nature with **low impact on residual risk** exposure.

Public Service Ombudsman for Wales (PSOW)

The Public Service Ombudsman for Wales annually writes to each Health Board in Wales and provides an overview of trends, performance and key messages arising from activity in the Ombudsman's office over the previous year. The letters are published on the Ombudsman's website - Annual Letters section: https://www.ombudsman.wales/?s=Annual+letters - the current letters are not yet published.

It is pleasing to note that the Health Board was below the average for complaints received and investigated with the Health Board average adjusted for population distribution.

Appendix A - Complaints made to PSOW

Health Board	Complaints Received	Received per 1000 residents
Aneurin Bevan University Health Board	142	0.24
Betsi Cadwaladr University Health Board	213	0.30
Cardiff and Vale University Health Board	89	0.18
Cwm Taf Morgannwg University Health Board	113	0.25
Hywel Dda University Health Board	88	0.23
Powys Teaching Health Board	10	0.08
Swansea Bay University Health Board	110	0.28
Total	765	0.24

For context, across the UHB in 2021/2022 we received over 3200 concerns.

Therefore, these figures demonstrate that less than 0.3 % of people who raised concerns with the UHB in 2019/20, approached the Ombudsman because they were dissatisfied with the Health Board response.

Local Health Board/NHS Trust	Out of Jurisdiction	Premature	Other cases closed after initial consideration	Early Resolution/ Voluntary Settlement	Discontinued	Other Reports Not Upheld	Other Reports Upheld	Public Interest Report	T
Cardiff and Vale University Health Board	23	7	30	11	1	2	6	1	8

It is pleasing to note that in this time period we had no concerns raised regarding the handling of complaints.

From the 89 concerns received by the Ombudsman, following initial review of our responses, a full investigation was undertaken into only some 9 cases and there were voluntary settlements agreed in 11 cases and 1 Public Interest report

In response to the annual letter, the Health Board has been asked to take the following actions by the Public Service Ombudsman for Wales

- Present my Annual Letter to the Board and share any feedback from the with my office.
- Continue to engage with our Complaints Standards work, accessing training for your staff, fully implementing the model policy, and providing complaints data.
- Inform me of the outcome of the Board's considerations and proposed actions on the above matters by 30 September.

We have met with the Ombudsman lead for the Complaints Standard Authority, which is intended to help support complaint handling staff in delivering excellent outcomes for service users. As part of their work, the Ombudsman's office is providing Training Sessions tailored to fit organisation's needs and provided without charge. Core modules focus on the complaints process, investigations, and communicating with complainants.

Soft skills modules explore additional sets of skills used in effective complaint handling and can provide an ideal refresher session for experienced staff.

We will ensure that the central concerns team will attend the modules when there is availability and we have been discussing a communications virtual module being developed for our UHB staff. This will be considered in the context of development of the Patient Experience framework.

The previous Internal Audit Review provided substantial assurance regarding the process within the Health Board for managing Ombudsman cases. All cases are managed via the corporate concerns team who support the Clinical Boards to respond to queries from the Ombudsman; cases are escalated to the Executive Team as required. All recommendations are monitored to completion and closure by the Ombudsman's office.

Further development of the Once for Wales Concerns system and the Service User Experience system, will enable more effective thematic and sentiment analysis to identify areas for

improvement. There should also be an increased ability to benchmark comparable data across Wales, to promote national learning and sharing of good practice and areas for improvement.

The Health Board has a robust process in place to manage concerns from the Ombudsman's office.

Ombudsman Standards Authority

The Complaints Standards Authority (CSA) was created under the Public Services Ombudsman (Wales) 2019 Act. The aim of the CSA is to drive improvement in public services. They have introduced a model Complaints Handling Process - this in the main mirrored work already in place in the Health Board and has not therefore required a change to our process.

Complaint Handling Processes – Statement of Principles Effective complaints handling processes should be:

1) Complainant Focused
2) Simple
3) Fair & Objective
4) Timely & Effective
5) Accountable
6) Committed to Continuous Improvement

Complainant Focused • The complainant should always be at the center of the complaints process. • Service providers need to be flexible when responding to complainants' differing needs.

Simple • Complaints processes should be well-publicized, have easy-to-follow instructions and have no more than two stages. • Information on advocacy services and support should be available. • Complaints responses should set out clearly the next stage and the right to approach the Ombudsman.

Fair & Objective • Complainants should receive a complete and appropriate response to their concerns. • Complainants and staff complained about, should be treated equally and with dignity.

Timely & Effective • Complaints should be resolved promptly, when possible • Investigations should be thorough, yet prompt. • Complainants should be kept informed throughout the progress of a lengthy investigation.

Accountable • Complainants should receive an honest and clear explanation of the findings of an investigation. • Service providers should explain to complainants what changes will be made if their complaint is upheld, whenever possible.

Committed to Continuous Improvement • Information from complaints should be collated and analyzed. • Data should be shared with the organization's senior leaders and the Ombudsman, to support improvement in complaint handling and in-service delivery. • Decision makers should regularly review the information gathered from complaints when planning service delivery.

National Reporting arrangements and definitions

The previous year saw a national change on the reporting of serious incidents which are referred to as NRI-Nationally Reported Incidents. Following publication of the National Patient Safety Incident Reporting Policy (the Policy) in May 2021, the NHS Wales Delivery Unit (DU), as the shadow form of the NHS Wales Executive, was commissioned by Welsh Government to lead the

implementation process. In turn, the DU established national mechanisms for collaborating and co-producing the national approach with all Welsh NHS organisations.

The current definition of a Nationally Reportable Incident is;

*A patient safety incident which caused or contributed to the **unexpected** or **avoidable death**, or **severe harm**, of one or more patients, staff or members of the public, during NHS funded healthcare.*

A patient safety incident occurs when an unintended or unexpected incident could have or did lead to harm for one or more patients receiving healthcare. We know the vast majority of incidents do not result in harm or significant harm, but do provide extensive opportunities for learning and improvements in safety to prevent future harm occurring. There will be occasions, however, when serious incidents do occur, resulting in serious harm, which can be life impacting or sadly result in an avoidable death. In such cases the consequences for patients, families and carers, as well as the staff providing that care, can be devastating. When incidents such as these occur, a comprehensive response is required to ensure immediate make safe actions are taken.

Never Events

Never Events may highlight potential weaknesses in how an organisation manages fundamental safety processes within existing systems. It is important therefore when a Never Event occurs, any failings in care are identified and investigated fully, but proportionately, regardless of the outcome, in line with the Patient Safety Incident Reporting Policy issued in May 2021. This ensures an understanding of where in the system safety measures have failed and by looking at what went wrong in the system will help organisations to learn lessons and take targeted actions to help prevent recurrence.

The updated list can be found on the NHS Wales Delivery Unit website Never Events - Delivery Unit (nhs.wales) https://du.nhs.wales/patient-safety-wales/.

In July 2022 a Welsh Health Circular was issued regarding changes to the Never Event list.

The Circular confirms: *'A recent review resulted in the decision to remove 'wrong tooth extraction' from the list of Never Events as conveyed in my letter of 22 July 2021. Incidents of this nature must continue to be reported and investigated locally and nationally if they meet the Patient Safety Incident Reporting Policy criteria. The Never Event list has therefore been updated to take account of this decision and supersedes WHC 2018/012. It also suspends undetected oesophageal intubation from the list whilst further work is undertaken'.*

Commissioned services

We commission some NHS services, from neighboring Health Boards / NHS trusts (including WAST) or outside of Wales. Where this happens, the following principles apply to ensure equity:

- the organisation where the patient safety incident occurred is responsible for reporting and investigating in line with its relevant national framework;
- when notified of an incident, the service commissioner should liaise with the investigating organisation as appropriate as part of the investigation.
- assurance should be sought that the patient and / or their family form part of the investigation process.
- assurance must be obtained to confirm any immediate make safes have been put in place which protects the ongoing safety of patients or consideration is given to remove patients from a particular care setting where appropriate.

• any incident learning should be shared with the service commissioner, as part of its internal assurance processes that commissioned services outside of its boundaries are safe and of high quality.

Near miss reporting

Near misses can provide a valuable source of learning. All NHS organisations are expected to share learning from near misses as part of the national reporting and learning framework. All patient safety incidents must be investigated proportionately in line with PTR requirements. The depth of the investigation will vary according to the issues under consideration and the level of harm caused.

In line with the revised Framework, all NHS organisations must ensure robust processes are in place to inform and assure their Boards, that the quality of their investigation processes is of a high standard, patients and families are being engaged in the investigation process, appropriate actions are being taken and that learning is being shared across their organisations to allow Boards to be assured that incidents have been dealt with appropriately and can be closed. Investigation outcomes will need to be shared nationally as set out in the implementation guide.

Early warning notifications

Early warning notifications replace 'no surprises' and should be used in circumstances where the Welsh Government needs to be alerted to an immediate issue of concern or prior warning of something due to happen which might relate to the following:

- has the potential to affect a number of patients/ staff / communities etc
- has a significant impact on service provision;
- may have an adverse impact in the media;
- might cause national or political embarrassment;
- following an inquest which has resulted in a Regulation 28 or public interest in a Public Services Ombudsman for Wales (PSOW) report
- a positive good news story. NHS organisations are expected to work closely with local and national communications teams where required to mitigate potential impact through the media.

Learning from Deaths

Following the atrocities from Harold Shipman and Mid Staffordshire Trust, mortality reviews were developed and introduced into NHS Wales as a system of learning and assurance. This was mandated from 2013 for hospital deaths and have been crucial in confirming important areas for continuous improvement, including sepsis and the recognition of the unwell and deteriorating patient. An All-Wales group was established to support the implementation and to guide a standardised approach.

The national group evolved to oversee the introduction of the Medical Examiner (ME) service and to develop a governance framework in line with Putting Things Right and Duty of Candour. Medical Examiners independently scrutinise all deaths that are not investigated by HM Coroner. There are three main drivers for the creation of Medical Examiners (MEs): improved patient safety; death certification accuracy and to support and inclusion of the bereaved relatives as highlighted in the Quality and Safety Framework: Learning and Improving (Welsh Government 2021).

Pre-COVID, about 200 deaths per month occurred in our hospitals. The aim was to send all hospital deaths to the ME office by the end of October 2021. The overall aim is for the ME to review all deaths in Wales, not just the hospital deaths. Themes and trends will also be collated on an All-Wales basis to highlight national priorities for improvement.

COVID Reviews and Investigations

Following the global Coronavirus pandemic, which has affected the lives of so many, there was a need to review the patients who have tested positive for Covid-19, whilst in-patients under the care of Cardiff and Vale Health Board. The reviews are measured and proportionate but of sufficient quality to identify learning and instances of harm. It is recognised that a hospital or care setting is a high-risk environment for the transmission of Covid-19. This transmission leads to a significant risk to patient safety, potentially leading to harm.

This project plan sits under the umbrella of the *'NHS Wales National Framework - Management of Patient Safety Incidents following Nosocomial Transmission of COVID-19 (2021)* which supports the *Communicable Disease Outbreak Plan for Wales (2020)* by identifying , reviewing and reporting patient safety incidents relating to nosocomial transmission of Covid-19 in line with the *National Health Service (Concerns, Complaints and Redress Arrangements) (Wales) Regulations 2011 – Putting Things Right (PTR)*.

Criteria for determining if a Covid-19 infection is healthcare-associated

HCAI category	Criteria
Community onset	Positive specimen date ≤2 days after admission to Trust
Indeterminate healthcare-associated	Positive specimen date 3-7 days after admission to Trust
Probable healthcare-associated	Positive specimen date 8-14 days after admission to Trust
Definite healthcare-associated	Positive specimen date 15 or more days after admission to Trust

Patient care reviews are undertaken in line with Putting Things Right regulations and should scope the level of potential risk the UHB is carrying, through the identification of learning and potential harm.

Definitions of harm relating to patient safety incidents are provided within the Putting Things Right guidance (PTR guidance v3 2013). The draft *'NHS Wales National Framework - Management of Patient Safety Incidents following Nosocomial Transmission of COVID-19 (2021)'* states that it is important to remember that in the context of this framework, 'harm' relates to the harm occurring as a result of nosocomial transmitted Covid-19. PTR is concerned not only with harm that has occurred as the result of a patient safety incident, but also harm that could have occurred as a result of that incident.

They define harm as:

Moderate Harm:

- Resulted in avoidable, semi-permanent injury or impairment of health or damage that requires intervention
- Additional interventions, required in addition to any baseline treatments for original hospitalisation treatment plan i.e. planned surgery/procedure
- Intended treatment is cancelled or significantly delayed
- Increase in length of stay by 4 – 15 days

Severe Harm:

- Issues that have resulted in avoidable, permanent harm or impairment of health, or damage leading to incapacity or disability
- Additional interventions required such as ITU care

- Cancellation or significant delay in urgent treatment
- Increase in length of stay by >15 days
- A concern outlining noncompliance with national standards with significant risk to patient safety

Covid-19 can lead to death soon after diagnosis, but it may also cause death many weeks later. Someone who tests positive can of course die from another cause such as cancer or heart disease at any time.

A death in someone who has tested positive becomes progressively less likely to be directly due to Covid-19 as time passes, and more likely to be due to another cause. However, there is no agreed cut-off after which Covid-19 can be excluded as a likely cause and sadly, some people die from their infection many weeks later.

Coronavirus can also contribute to a death without being the main or underlying cause. The World Health Organisation (WHO) recognises this complexity and states that: A Covid-19 death is defined for surveillance purposes as a death resulting from a clinically compatible illness in a probable or confirmed Covid-19 case, unless there is a clear alternative cause of death that cannot be related to Covid-19 disease (e.g. trauma). This definition therefore requires a clinical assessment of each case.

Two toolkits were developed in response to the need to review patient care under the circumstances outlined above - a *Rapid Patient Assessment* and the *Covid-19 Patient Investigation Toolkit*.

The *Rapid Patient Assessment Toolkit* is to be primarily utilised for patients who acquired Covid-19 on day 8 onwards into their healthcare stay (swab taken on day 8 onwards). The *Covid-19 Patient Investigation Toolkit* will be commenced in the event that harm has been identified or where death has occurred and Covid-19 is listed on the death certificate.

In the event of Nationally Reported Incident (NRI) being identified, then a root cause analysis will be undertaken in line with the current NRI framework.

The purpose of undertaking a review into a patient's care is to identify the likely root cause of acquisition of Covid-19, review the patient's care and identify any failings which may have contributed to harm.

Learning enables the identification of actions required to reduce future risk, these will be recorded in a Clinical Board Action Plan and feed into an over-arching Cardiff and Vale Action Plan, to ensure widespread cross Board learning and enable future planning.

Clinical Effectiveness Committee

In December 2020 the Clinical Effectiveness Committee (CEC) was established and rapidly gathered momentum.

Clinical Audit is an integral component of the quality improvement process and is embedded within the Welsh Healthcare Standards. NHS Wales needs to be a learning organisation which regularly seeks to measure the quality of its services against consistently improving standards and in comparison, with other healthcare systems across the UK, Europe and the World.

In addition, the Committee discusses any Patient Safety Notices where compliance is outstanding.

Documents of Interest links and information

A Healthier Wales: https://gov.wales/healthier-wales-long-term-plan-health-and-social-care (AHW) sets out a long-term vision that everyone in Wales should have longer, healthier and happier lives. It proposes a whole-system approach to health and social care which is equitable, and where services are designed around individuals and groups based on their unique needs and what matters to them, as well as quality and safety outcomes. The first NHS Wales core value described in A Healthier Wales is "Putting quality and safety above all else – providing high-value evidence-based care for our patients at all times."

Healthcare organisations in Wales are focused on meeting the quadruple aim of excellence in population health and wellbeing, personal experiences of care, best value from resources and an engaged and committed workforce. Our philosophy of value-based, prudent, health and care underpins this and will continue to be a distinctive feature of the Welsh system.

The recent Health and Social Care (Quality and Engagement) (Wales)Act2020: https://www.legislation.gov.uk/asc/2020/1/contents

which places both an enhanced duty of quality and an organisational duty of candour will strengthen the approach to high quality, safe care.

The recently-published National Clinical Framework: https://gov.wales/national-clinical-framework-learning-health-and-care-system

provides a clinical interpretation of A Healthier Wales and describes a learning health and care system, centered on clinical pathways that focus on the patient, grounded in a life-course approach. In recent years, major health condition delivery plans set out policy expectations for high priority clinical services. These plans came to an end in December 2020 and as described in the National Clinical Framework, will gradually be replaced by Quality Statements. These successor arrangements will help to set out what Stakeholder's think are important quality attributes of high priority clinical areas, such as cancer, heart disease and stroke services; as well as services such as critical care and end of life care.

Welsh Government has recently published Looking Forward, to help health and social care emerge from the pandemic, describing the challenge as building the integrated health and social care service that we want going forward and to deal with the long-term impacts of COVID-19. The opportunity is to change for the better, recognising that COVID-19 is still with us.

A key aspect to this recovery is ensuring that care is as safe as possible and that harm is minimised. The five harms we describe in health and care in Wales, are:

1. Direct harm from COVID-19 itself
2. Indirect harm from COVID-19 due an overwhelmed health and social care system and reduction in healthcare activity as a result
3. Harm from population-based health protection measures i.e. educational harm
4. Economic harm both directly and indirectly as a result of COVID-19 i.e. unemployment as a result of lockdown
5. Harm as a result of exacerbation or introduction of new inequalities in society

The OECD Review of Health Care Quality:

https://www.oecd.org/unitedkingdom/oecd-reviews-of-health-care-quality-united-kingdom-2016-9789264239487-en.htm

published in 2016 commented that quality is at the heart of the healthcare system in Wales however it did make recommendations to strengthen what has already been built. These include a stronger relationship between Health Boards and Welsh Government, more visible accountability within Health Boards, with the technical, managerial and leadership capacity to drive up standards.

The Welsh Government's Health and Care Standards:

https://gov.wales/health-and-care-standards

must also be taken into account by organisations in their discharging of the duty of quality. This framework of standards is designed to support the NHS and partner organisations in providing quality services across all healthcare settings. These standards describe what the people of Wales can expect when they access health services.

Placing a Duty of Candour on NHS organisations, including providers of primary care, will improve service user experience, communication and engagement between the NHS and its service users. It will build on the work that has already been undertaken through the Putting Things Right:

https://gov.wales/nhs-wales-complaints-and-concerns-putting-things-right#:~:text=The%20process%20for%20raising%20concerns%20or%20complaints%20in,a%20carer%2C%20friend%20or%20relative%20to%20represent%20you.

arrangements for dealing with concerns, complaints and incidents.

This framework recognises that enabling people to access services using the Welsh language is an intrinsic part of the quality of care and helps to ensure the safety, dignity and experience of Welsh speakers. Actions described within this framework will be developed in line with this principle and the More Than Just Words framework.

It is also important that we learn from specific patient safety and care issues that may emerge. In 2020, First Do No Harm, the report from the Independent Medicines and Medical Devices Safety Review, looked at the use of pelvic mesh as well as the use of sodium valproate and the harm caused to women and children as a result of these interventions. This report was specifically looking at the use of these interventions in England, but has valuable learning for the NHS in implementing the action points contained within the HEIW workforce strategy,

A Healthier Wales: Our Workforce Strategy for Health and Social Care will help organisations address staff shortages by improving staff retention as well as recruitment. The Strategy aims to enrich wellbeing and working experience for those who currently provide health and social care, including volunteers and carers and to promote health and social care as the sector of choice for the future workforce. The overarching aim for 2030 is to provide the right number of motivated, dynamic and appropriately skilled people to help meet the health care needs of the population they serve in a sustainable, cost-effective way.

Duty of Candour

This must be prior to any wider learning identified from an investigation into the event and to ensure those affected are fully supported and involved in any investigation process as required.

Sometimes a serious "near miss" can provide important learning and therefore also needs careful consideration to prevent future harm. Patient safety incidents can be single isolated events or

multiple recurring events, which can signal more systemic failures in care, including omissions in care provision or demonstrate system weaknesses. They can also include events which indirectly impact patient safety or an organization's ability to deliver a service, such as a failure in an IT system.

Incidents should be investigated appropriately and proportionately with actions taken accordingly, in line with PTR requirements.

The reporting of patient safety incidents at a national level will:

- provide oversight and assurance relating to the most 'serious' incidents occurring in healthcare
- enable the identification of organisational and/or system risks
- Inform learning and action, including the development of patient safety alerts and notices, policies and improvement programs, national priorities, outcome measures and any potential service reforms.

Phase one of the Policy came into effect on 14 June 2021. This phase primarily related to reporting individual incidents with harmful outcomes to the NHS Wales Delivery Unit.

Phase two delivered a significant shift in national incident reporting, with the focus expanding beyond individual incidents causing significant harm to also look at learning from across a range of incidents and harm outcomes. There was also a pressing need to provide clarity in relation to reporting hospital acquired infections, in particular nosocomial acquired Covid-19. The phase two incident work has been undertaken in full alignment with the national work around nosocomial Covid-19.

As with concerns, it is important that the investigation of patient harm continues, to ensure good quality care provision is maintained and the learning shared. For this reason, organisations must report and investigate all incidents locally in line with PTR (Putting Things Right) guidance.

NHS organisations are not required to undertake full root cause analysis for each and every incident. The investigations carried out should be proportionate to the incident being reviewed and should ensure immediate 'make safes' are put in place with all learning shared across the organisation in the usual way.

Never Events, in-patient suicides, maternal deaths and avoidable healthcare acquired pressure damage and incidents affecting a significant number of patients, have continued to be reported to the Delivery Unit (DU) immediately. Where there is uncertainty as to the level of harm caused and whether there are causative factors related to their healthcare provision, all NHS Organisations now have 7 days to fact find and report to the DU.

The formal 60-day performance target for SI closure reporting was removed at the commencement of the pandemic. During this time, we continue to work towards the 60 days with the emphasis on proportionality of investigation for all incidents.

Future Considerations

It is also important to consider implementation of the forthcoming Duties within the Health and Social Care (Quality and Engagement) (Wales) Act 2020. The Duty of Quality requires organisations to set out all decisions that are taken to secure improvement in the quality of services provided within the NHS in Wales, in the journey towards ever higher standards of person-centered health services.

The Duty of Candour focusses on the need to be open with patients, families and carers when things go wrong, building on the requirements already set out in PTR. Evidence suggests that increased openness, transparency and candour are associated with the delivery of higher quality health and social care. When the Duty of Candour is implemented (in April 2023), the outcome

of candour investigations will also be an important source of learning and improvement. As set out in the guidance, the new Duty of Candour requires NHS bodies to be open and transparent with patients and their families when the duty of candour applies.

The Duty is triggered when:

- A service user to whom health care is being or has been provided by the body has suffered an adverse outcome; and the provision of health care was or may have been a factor in the service user suffering that outcome.

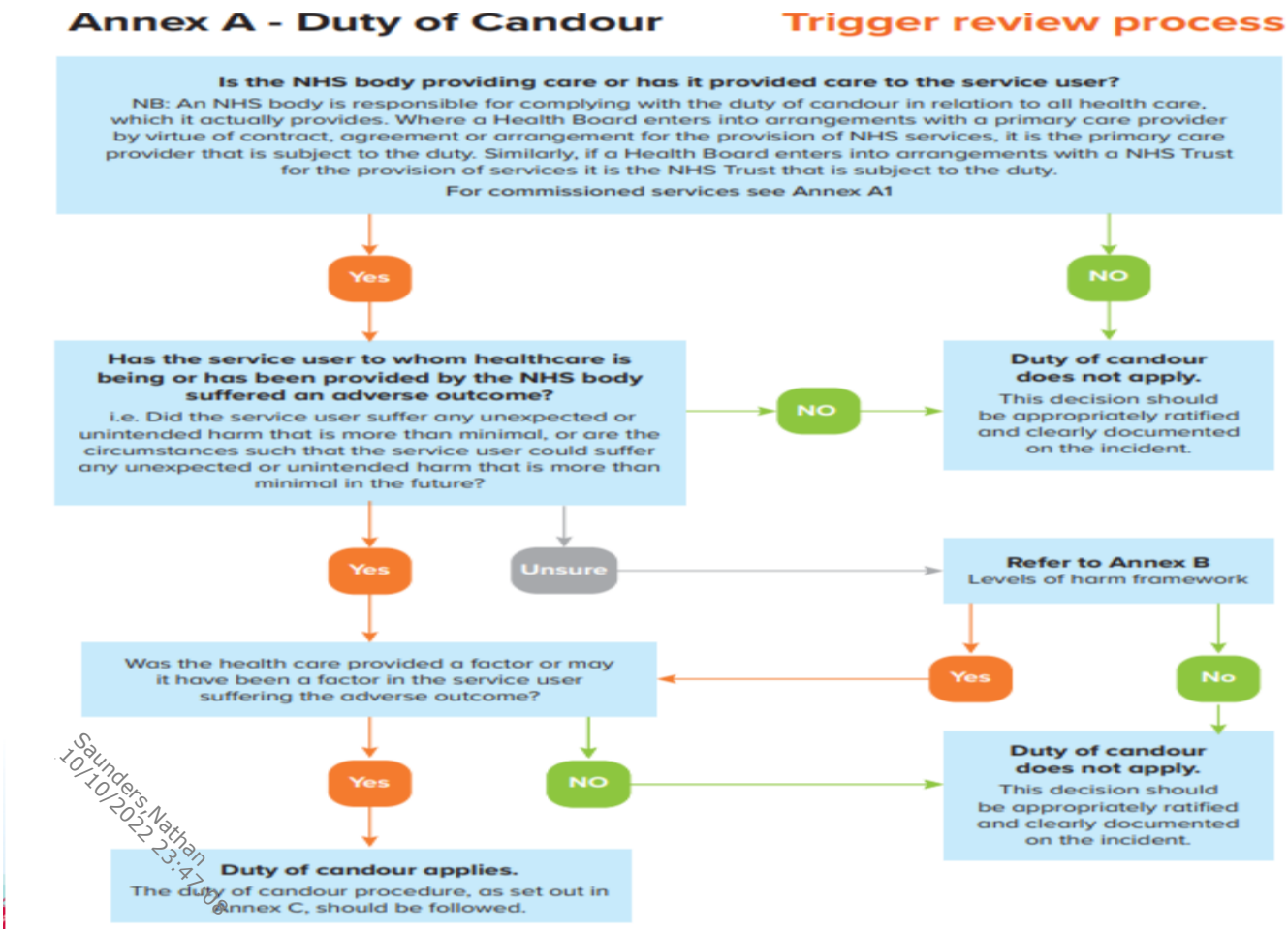
A service user is treated as having suffered an adverse outcome if the user experiences, or if the circumstances are such that they could experience; any unexpected or unintended **harm that is more than minimal**. For the purposes of the Duty of Candour, harm includes psychological harm and in the case of service user who is pregnant, loss of or harm to the unborn child. **Further consideration is being given to what is meant by psychological harm.**

In both England and Scotland, harm that triggers the Duty of Candour is “moderate” harm and above, (moderate and severe harm or death).

It is important to acknowledge that the threshold for the Duty of Candour trigger is slightly different to the NRLS threshold, in that, its trigger is specific to service user/s experiences that resulted or could have resulted in, any unexpected or unintended harm that is more than minimal.

The Duty of Candour documentation is currently available for a consultation period until 13 December.

: [The Duty of Candour | GOV.WALES: https://gov.wales/duty-candour](https://gov.wales/duty-candour)



1. **What happens when a person is contacted?**

When the **Duty of Candour** applies, the person who has been affected must be contacted.
The person should be contacted straight away. Not at the end of an **investigation**.
It is ok to contact a person who is acting on someone's behalf. For example, a family member, if that has been agreed.
It is important to follow laws about keeping people's information private.
The NHS will need to decide who is the best member of staff to get in contact with the person.
They should have enough experience and be able to answer questions about the **Duty of Candour**.
They need to say sorry about what has happened. And explain what will happen next.
They also need to offer any support the person might need.
As this is statutory guidance we will need to report annually

Reporting requirements

Publish an Annual Report

- State how often the Duty of Candour has been triggered during the reporting year;
- Give a brief description of the circumstances in which the duty was triggered;
- Specify any steps taken by the body with a view to preventing similar circumstances from arising in the future.
- Commissioned providers report to the Commissioning NHS body who then include their data in their annual report
- NHS bodies monitor implementation through oversight processes e.g. JET. IPQD
- HIW will include compliance when inspecting

Recommendation:
The Committee is requested to: a) **note** the information and to consider the future requirements of the Duty of Candour.

Link to Strategic Objectives of Shaping our Future Wellbeing: *Please tick as relevant*			
1. Reduce health inequalities	✓	6. Have a planned care system where demand and capacity are in balance	
2. Deliver outcomes that matter to people	✓	7. Be a great place to work and learn	
3. All take responsibility for improving our health and wellbeing		8. Work better together with partners to deliver care and support across care sectors, making best use of our people and technology	
4. Offer services that deliver the population health our citizens are entitled to expect	✓	9. Reduce harm, waste and variation sustainably making best use of the resources available to us	✓
5. Have an unplanned (emergency) care system that provides the right care, in the right place, first time		10. Excel at teaching, research, innovation and improvement and provide an environment where innovation thrives	

Five Ways of Working (Sustainable Development Principles) considered *Please tick as relevant*									
Prevention		Long term		Integration		Collaboration	✓	Involvement	✓

Impact Assessment: *Please state yes or no for each category. If yes please provide further details.*
Risk: Yes
The Ombudsman reviews provide an independent level of scrutiny

Safety: Yes
Delays in investigations presents a delay in identified learning and mitigation being put in place at the earliest opportunity the Quality indicators should help when viewed collectively to pre-alert to areas of concern
Financial: Yes
Failure to identify learning from themes will lead to increased harm and litigation
Workforce: Yes
Through the Ombudsman reports we monitor any workforce issues
Legal: Yes
We need to adhere to the relevant legislation
Reputational: Yes/No
There is media interest in PSOW reports
Socio Economic: Yes
Consideration of socio-economic disadvantage needs to be further explored through interrogation of the quality indicators to the level of low super output areas of social deprivation in comparison to areas of affluence
Equality and Health: Yes
When reviewed in detail it should be considered if any reports demonstrate equality and health inequities
Decarbonisation: Yes/No

Approval/Scrutiny Route:	
Committee/Group/Exec	Date:

Report Title:	Quality, Safety and Experience information Carers Annual Report			Agenda item:	6
Meeting:	**QUALITY, SAFETY& EXPERIENCE COMMITTEE – Special Meeting**	Public	✓	Meeting Date:	11/10/22
		Private			
Status	Assurance	✓	Approval		Information
Lead Executive:	Executive Nurse Director				
Report Author	Assistant Director of Patient Experience				

Background and current situation:

This document sets out the report for 2021/22 of the Cardiff and Vale University Health Board, Cardiff and Vale of Glamorgan Local Authorities, Cardiff Third Sector Council (C3SC) and Glamorgan Voluntary Services (GVS), highlighting the achievements made in line with the three national priorities:

- Supporting life alongside caring
- Identifying and recognizing carers
- Providing information, advice and assistance:

It will also describe how the funding allocation from Welsh Government has been utilized to support carers throughout Cardiff and the Vale of Glamorgan

Executive Director Opinion/Key Issues to bring to the attention of the Board/Committee:

The report highlights some of the innovation that developed as a response to the pandemic when support for carers had to be provided in different ways

The Committee is requested to:

a) Note the report

Link to Strategic Objectives of Shaping our Future Wellbeing:
Please tick as relevant

1.	Reduce health inequalities	✓	6.	Have a planned care system where demand and capacity are in balance	
2.	Deliver outcomes that matter to people	✓	7.	Be a great place to work and learn	
3.	All take responsibility for improving our health and wellbeing		8.	Work better together with partners to deliver care and support across care sectors, making best use of our people and technology	

4. Offer services that deliver the population health our citizens are entitled to expect	✓	9. Reduce harm, waste and variation sustainably making best use of the resources available to us	✓
5. Have an unplanned (emergency) care system that provides the right care, in the right place, first time		10. Excel at teaching, research, innovation and improvement and provide an environment where innovation thrives	

Five Ways of Working (Sustainable Development Principles) considered *Please tick as relevant*									
Prevention		Long term		Integration		Collaboration	✓	Involvement	✓

Impact Assessment: *Please state yes or no for each category. If yes please provide further details.*
Risk no
Safety: no
Financial: no
Workforce: Yes
We encourage use of the centers for work-based session such as immunization and citizens advice which are open to our staff
Legal: Yes
We need to adhere to the relevant legislation
Reputational: No
Socio Economic: Yes
Consideration of socio-economic disadvantage needs to be further explored through interrogation of the quality indicators to the level of low super output areas of social deprivation in comparison to areas of affluence
Equality and Health: Yes
When reviewed in detail it should be considered if any reports demonstrate equality and health inequities
Decarbonisation: Yes/No

Approval/Scrutiny Route:	
Committee/Group/Exec	Date:

Saunders,Nathan
10/10/2022 23:47:08

MAY 2021 - MAY 2022

ANNUAL CARERS REPORT

VALE of GLAMORGAN
BRO MORGANNWG

Patient Experience
Profiad y Claf

CARDIFF
CAERDYDD

GVS

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board

C3SC
Cardiff Third Sector Council
Cyngor Trydydd Sector Caerdydd

INTRODUCTION

This document sets out the report for 2021/22 of the Cardiff and Vale University Health Board, Cardiff and Vale of Glamorgan Local Authorities, Cardiff Third Sector Council (C3SC) and Glamorgan Voluntary Services (GVS), highlighting the achievements made in line with the three national priorities:

- Supporting life alongside caring
- Identifying and recognising carers
- Providing information, advice and assistance

It will also describe how the funding allocation from Welsh Government has been utilised to support carers throughout Cardiff and the Vale of Glamorgan.

The 2011 census reported that within Cardiff and Vale of Glamorgan we have approximately 50,580 carers. As we await the findings from the 2021 census, we are already aware that the number of unpaid carers has increased dramatically, as a result of the Covid pandemic. At the height of the pandemic a report by Carers Wales stated that, in Wales alone, the number of unpaid carers rose to 683,000. It has also been reported that throughout the pandemic unpaid carers saved public services, in wales, £33 million every day, equating to £12 billion over a year. It is important to note that at **23%** the current percentage of the population who identify as unpaid in Wales is above the UK average, with Wales also having the highest percentage of unpaid carers over 65 and young carers in the UK. Despite this, the latest Carers Week report suggests that in Wales **73%** of people do no think the role of unpaid carers is valued by the general public.

Organisations such as Carers Wales and Carers Trust have been highlighting the struggles of unpaid carers prior to the pandemic, however these struggles have been compounded by Covid-19 and recent economic burden. The most recent Carers Wales State of Caring Report states that **8%** of unpaid carers can not afford their utility bills and **23%** did not feel confident that, over the coming year, they would be able to manage financially. Over **50%** of unpaid carers were using credit cards, overdrafts or borrowing from family and friends to make ends meet.

Although improving the lives of unpaid carers is a priority of Cardiff and Vale University Health Board, Cardiff and Vale of Glamorgan Local Authorities, Cardiff Third Sector Council (C3SC) and Glamorgan Voluntary Services (GVS) there is still much to be done to provide support for all carers, ensuring they feel their contribution is valued and appreciated.

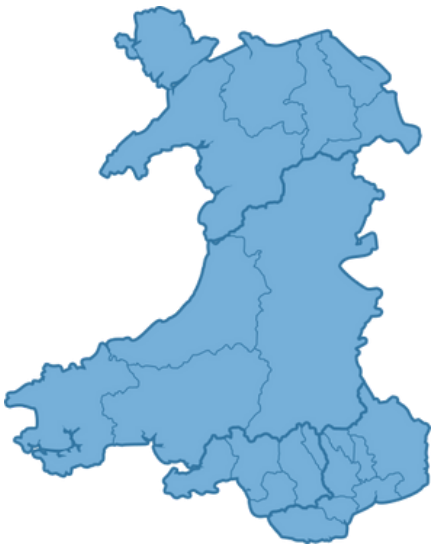
The Health Board and both Local Authorities continue to work in partnership with the Third Sector to deliver service improvements for carers, all aided by the £1m funding that has once again been provided by Welsh Government. However, even as we are beginning to move out of the pandemic the affects it has had on unpaid carers can not be underestimated. Services and support for unpaid carers have been significantly reduced, because of the pandemic, with some Third Sector services, having to stop all together. Fortunately as Government covid restrictions have been lifted, work streams and initiatives that had to be placed on hold, are able to restart and begin to support unpaid carers.

Carers leads from each organisation continue to work together to raise awareness of unpaid carers and their role, improve the information and signposting provided, as well as looking how support can be improved and finding new ways to provide services. However, it is important as we develop and improve these services that we engage with unpaid carers and ask what matters to them.

This report details the collaborative work that has been undertaken between May 2021 and May 2022.

36%
of unpaid carers in Wales said that they often or always felt lonely

60%
of unpaid carers in Wales reported their physical health had worsened since the pandemic



71%
of unpaid carers in Wales said their mental health had worsened since the start of the pandemic

66%
of unpaid carers in Wales believe that there will be further reduction to support services

THE REAL COST OF CARING

Prior to the pandemic it was estimated that each year the support provided by unpaid carers, in Wales, is worth £8.1 billion. However, at the height of Covid-19 research by Carers Wales highlighted that this contribution rose to around £33 million a day with the care they provided. Unfortunately in spite of this contribution to society unpaid carers still feel that their input is overlooked by Government and society in general.

The personal cost of providing unpaid care for a family member or friend is huge with many unpaid carers health and well-being suffering as a result. This was only been compounded by lockdowns and covid restrictions. Even before the pandemic unpaid carers have voiced that they have struggled to access meaningful breaks and over the past two years these vital respite services have significantly reduced. The Carers Week 2021 report 'Breaks or Breakdown' highlighted that **72%** of unpaid carers, in Wales, reported not having any breaks during the pandemic. In addition **30%** of those who were managing to get a break were using them to complete tasks such as housework, and not actually taking a break. This will, without doubt, have a detrimental effect on the overall health and well-being of unpaid carers.

Many carers voice that while caring for someone is very rewarding, it can also have it's challenges. The 'Breaks or Breakdown' report released in 2021 highlights that carers in Wales are struggling to continue to care and they are reporting high levels of stress and fatigue. Nearly three quarters, **73%,** of respondents stated that they were exhausted and worn out by their caring role, and **61%** were worried how they would continue to care without a break. Worryingly a number of unpaid carers where close to breaking point, with **40%** stating that they felt unable to manage their caring role.

These issues, plus numerous others, highlight the increased need for urgent local support for unpaid carers. There is a clear commitment from Cardiff and Vale University Health Board, Cardiff Council, Vale of Glamorgan Council, and our Third Sector partners to identify and support unpaid carers at the earliest point and improve services.

PRIOTIRTY: IDENTIFYING AND RECOGNISING CARERS

The Health Board and both Cardiff and the Vale of Glamorgan Local Authorities, in partnership with the Third Sector, are committed to making unpaid carers visible, valued and supported. According to the State of Caring Wales UK report 2021 there needs to be a systematic awareness raising through out key professions and organisations. This would help to identify carers earlier to ensure they receive, information, support and advice at the right time.

The identification of unpaid carers continues to be a challenge, with one of the barriers being the confusion around the term 'carer' and some believing this is a paid role undertaken by Health or Social Care teams. In recognition of this we continue to ask *'Do you look after someone?'.* We hope that this approach will help to identify some of the hidden unpaid carers in our communities, and that as a result we will see an increase to the numbers of identified unpaid carers reported.

It is vital that we are identifying unpaid carers as early as possible so we are able to advise them in maintaining their own health and well being which, in turn, will enable them to continue in their role. This support can be successfully provided by healthcare teams working in partnership with local authorities and the third sector.

HEALTH BOARD STAFF TRAINING AND AWARENESS SESSIONS

As covid restrictions start to lift within Healthcare settings staff training and corporate inductions will begin to recommence. The Carers Lead and Information and Support Centre Manager have used the time during restrictions to update all training materials to ensure that the most up relevant information is provided. The team are in contact with the Learning and Education Department to ensure that this training is once again included in their training programme.

In addition the Carers Lead and Information and Support Centre Manager are developing a training session for GP Unpaid Carers Champions. This training will be for new and existing GP Unpaid Carers Champions to update their knowledge on Unpaid Carers and the challenges they are facing post covid.

SOCIAL MEDIA

Over the last two years, largely to the pandemic, we have seen an increase in the number of people using the internet as an information source. As a team we have continued to increase our social media presence, using it to inform unpaid carers on current hospital restrictions and visiting guidance.

The Carers Lead has been working on ways to increase the social media reach of the team and has begun to explore different social media platforms. In addition we have continued to use Twitter as a way to let staff and the community know who they can contact if they need support, to raise awareness of carers, advertise carer's events, and promote national campaigns such as Carers Week, Carers Rights Day and Young Carers Awareness Day. The use of social media has helped us to reach a wider audience, however, we are conscious that this is not how everyone would like to receive there information.

Cardiff and Vale University Health Board has a comprehensive social media communications plan for all national campaigns to ensure that consistent messaging is being used in the build up to and during the campaign.

We are now working towards a Unpaid Carers Communication Plan for the team helping us to target our messages for different carers and ensuing it is reaching them on the platforms they use more frequently.

COMMUNITY EVENTS

Pre-pandemic the Carers Lead would regularly attend local community events to raise awareness of who unpaid carers are and the challenges they face. Due to the restrictions during the pandemic all large events were cancelled, however, some did continue virtually. These virtual events were attended by the Carers Lead, but it was difficult to speak to participants on an individual level.

As restrictions have begun to lift in the both the community and healthcare settings large information events are once again able to go ahead. The first of which will be the Minority Ethnic Communities Health Fair, where the Carer Lead and Information and Support Centre Manager will have an unpaid carers stand providing information on unpaid carers rights and the local services available to them.

UNPAID CARER STORY

The Covid-19 pandemic has been a stressful and worrying time for everybody and has made situations for unpaid carers, like attending Emergency Units with the person you care for, increasingly difficult. Due to social distancing rules Emergency Units were encouraging those who needed to attend to come alone, however, Welsh Government had stated that an unpaid carer could attend if the person they cared for needed them to. Unfortunately on some occasions unpaid carers were not being allowed to attend, this was sometimes due to the fact that the Emergency Unit was full to capacity, but on some occasions it was due to a lack of understanding of who unpaid carers were. On one such occasion, where an unpaid carer was refused entry to the Emergency Unit with her husband, the unpaid carer contacted the Patient Experience Team to provide a digital story to be used as a learning tool. Link and QR code to the story below;

https://youtu.be/7qXgYuXHENo

The story was shared with at the Executive Board meeting and with the Emergency Unit Senior team. In response to the story provided the Carers Lead has been working with the Senior Nurse in Emergency Medicine to look at initiatives to improve the experience of unpaid carers in an emergency setting, and unpaid carer awareness training for staff.

UNPAID CARER ENGAGEMENT

During the Pandemic, as a team, we were keen to continue to gather feedback from patients, relatives and unpaid carers. In order to do this we had to think of new ways of reaching unpaid carers to complete surveys and undertake unpaid carer stories. The Feedback Manager along with the Carers Lead developed a number of online surveys which we advertised via social media, webpages, and using QR Codes on posters. Some of the surveys we undertook are listed below;

- Dragons Heart Relatives Survey
- Hospital Visiting Survey
- Mass Vaccination Centre Survey
- Unpaid Carers Information Survey

As well as our own surveys the Patient Feedback Manager, and the team, have supported in the development of an Unpaid Carers Charter feedback survey. In addition the team has also supported a number of virtual town hall events including a Physiotherapy service feedback event and a Patient Safety and Experience Framework event. These events have allowed unpaid carers to have a voice in service development and shaping future priorities.

As restrictions lift the Carers Lead and Information and Support Manager are keen to continue to engage with unpaid carers, to understand what matters to them. An unpaid carers discharge survey is currently in development, along with a plan to undertake some face to face engagement events with local carers groups from August 2022 onwards.

PRIORITY: PROVIDING INFORMATION, ADVICE AND ASSISTANCE

Having the right information at the right time is vital for unpaid carers to ensure they are aware of their entitlements and what support is available to them. The Carers Week Report: Making Caring Visible, Valued and Supported, published in 2022, stated that for people who are not currently in a caring role one of the main concerns was not knowing or understanding what help was available. They also reported that after Local Council Services it would be family/friends or the GP who they would turn to for support, if they became unpaid carers. This just highlights the need for initiatives such as the GP Carer Accreditation to ensure front line staff are confident in signposting carers to support. It is also important however that staff in all aspects of Health and Social Care are trained to identify unpaid carers so that information, advice and assistance is offered at the earliest stage possible. Research tells us that the earlier we put interventions or services in place, for unpaid carers, the less likely they are to reach crisis point.

Worryingly the recent State of Caring Wales report has highlighted that **37%** of unpaid carers did not know what a Carers Assessment was and of those who had undergone the assessment **72%** stated that it have not adequately considered their physical and mental needs. In addition **58%** said that their ability and willingness to provide the care was not looked at properly. This clearly demonstrates the need for more work to be done to raise awareness of unpaid carers rights to a Carers Assessment, what they are and how to request one.

The recent pandemic made accessing information even more difficult due to lockdowns, shielding, and services such as GP Surgeries, Community Hubs, libraries and Community Centre's having to close. These circumstances meant that many unpaid carers lost their access to reliable sources of information.

The following section sets out the work that services have undertaken to adapt to new ways of working as well as improving information and signposting for carers. This work will enable carers to access the vital information and services that they need, when they need them.

40%
of people in wales who are not currently unpaid carers said they would contact their GP if they became unpaid carers and needed information.

37%
of unpaid carers in wales do not know what a Carers Assessment is.

40%
of unpaid carers in Wales were unaware of the services and sources of support available to them locally

CARDIFF AND VALE CARERS GATEWAY

The Care Collective (formally Carers Trust South East Wales) provides a Carers Gateway Service on behalf of the Health Board. This service provides carers with practical and emotional support, as well as helping unpaid carers to navigate the services available to them.

Since it's launch, March 2020 the service has operated a helpline every working day (with the exception of public holidays). This year alone the Carers Well-being Team have taken 244 referrals, to help unpaid carers practically and emotionally. It is important to note that of the 244 referrals **86%** were previously unknown to the Local Authorities.

With the lifting of lockdown restrictions, the team has had the opportunity to launch their outreach work into the community, starting with sessions at Chapter Arts Centre, Cardiff, allowing them to raise awareness of their service in the locality.

As part of the Carers Gateway a Counsellor as been working with unpaid carers in the Vale of Glamorgan area. This service however will be increasing with the addition of 2 student counsellors. This will allow the team to not only extend their criteria for support, but to also extend there reach to unpaid carers in the Cardiff Area.

INFORMATION AND SUPPORT CENTRES

Over the last 6 months, as covid restrictions have begun to lift, we have been able to re-open our Information and Support Centres. We have also been able to re-introduce Health Board volunteers back to the centres to support patients, visitors and staff locate information.

Visitors to the centre are still relatively low compared to the pre-covid statistics, however, each centre is seeing an increase in the number of enquiries. At the last update, in March, volunteers and the Information and Support Centre Manager had supported 69 unpaid carers with information, or signposting them on to local services.

Over the coming months the Information and Support Centre in University Hospital Llandough will host a weekly drop in session specifically for unpaid carers to speak to the Carers Lead, to get information and advice about the local and national services available to them.

CARDIFF AND VALE CARERS SUPPORT AND INFORMATION NETWORK GROUP (CSING)

Cardiff and Vale Carers Support and Information Network Group (CSING) brings together staff from the third sector, local authorities and health board who plan and deliver services for carers in the region.

CSING is facilitated by GVS, in liaison with Cardiff Third Sector Council (C3SC), and has been meeting for over 14 years, beginning as a Vale group before expanding to Cardiff. It now has over 40 members. Throughout the pandemic the network moved to a virtual forum, which helped to increase attendance to the group has continued in this format even as restrictions are lifting. Cardiff and Vale Carers Gateway host the quarterly meetings and the forum provides a good opportunity to share information, highlight current and new services, identify gaps and issues which affect carers and support partnership working across sectors. Issues raised can be highlighted via regional partnerships and planning groups.

VOLUNTEER UNPAID CARER NAVIGATOR ROLE

This year during Carers Week we announced the launch of a new volunteer role, developed with the Patient Experience Volunteer Managers. We are initially recruiting to this role from current experienced Information and Support Centre volunteers, who will be provided with extra bespoke unpaid carer awareness training. The aim will be to enable them to support unpaid carers to navigate areas of Health and Social Care such as hospital discharge and the carers assessment process.

UNPAID CARERS GP ACCREDITATION

National and Regional Carers Reports continue to highlight that the majority of unpaid carers would use their local GP Practice as a source of information for their caring role. This had led to the Health Board, Local Authorities and Third Sector to utilise a collaborative approach to increase the identification and recognition of carers within Primary Care. The GP Carers Accreditation consists of two criteria levels, Bronze and Silver, which GP Practices are assessed against in order to gain the award. Currently representatives from the Health Board and Local Authority are involved in the assessment and support process, however, this process is currently being updated and we hope to involve the Volunteer Unpaid Carer Navigators in the new assessment process.

As part of the accreditation each practice nominates a Carers Champion who is able to provide support and advice to carers and is the primary point of contact for the Carers Lead and Information and Support Centre Manager in Cardiff and the Carers Development Officer in the Vale of Glamorgan. As with a number of initiatives due to the pandemic the GP accreditation scheme was placed on hold, however pre pandemic engagement in the scheme had increased year on year with approximately **80%** of GP surgeries in Cardiff and the Vale of Glamorgan engaging with the scheme at varying levels.

Although the pandemic had hindered progress of the accreditation scheme the Carers Lead and the Information and Support Centre Manager have used this time to update and standardised resources and our training slides. We are now in the process of re-engaging with GP Surgeries and working on setting up a training event for new and existing Carers Champions to update their knowledge on unpaid carers and the challenges they are facing post covid.

Training slide examples

CARER FRIENDLY ACCREDITATION

Since 2016 The Care Collective (formally Carers Trust South East Wales) have been successfully implementing their Carer Friendly Accreditation throughout Cardiff and the Vale. The aim is to improve, share and recognise support for carers across a wide range of services. Initially commissioned by Cardiff and Vale University Health Board and Cardiff and Vale of Glamorgan Councils, the Accreditation Scheme has developed from focusing solely on health and social care to including communities and employers who want to support unpaid carers. From this partnership a Framework was developed and the Accreditation broken down into five standards:

Those who participate can achieve two levels within the Accreditation: Carer Friendly and Carer Friendly Advanced. Service areas complete a self-assessment tool, provide a portfolio of evidence to prove that they meet the criteria and that portfolio is then put forward to a Carers Review Panel who review the portfolios and either approve the accreditation or provide constructive feedback on areas for improvement. This panel consists of unpaid carers, Health Board, Local Authority and Third Sector representatives; each providing a unique perspective.

Once again the recent pandemic has had effect on the progress of the Carer Friendly Scheme, however, as services start to open up discussions with teams around the accreditation, and taking on training are underway. Despite the barriers that that the team faced throughout the pandemic they have been able to engage a growing number of professionals and organisations. New ways of working have been put in place such as putting the accreditation process on Microsoft forms and undertaking meetings over Microsoft teams. During this quarter the Dementia Learning and Development Team in University Hospital Llandough have achieved the accreditation with another **5** services across health and Social Care working towards the accreditation and another **36** services expressing an interest as covid restrictions continue to lift.

The Carer Friendly Team have also been working with organistaions to provide a short Carer Awareness training session. The training session looks at themes, such as, who are ours unpaid carers, what challenges do they face and what support is available to them. Between April 2020 - March 2021 the team have undertaken **19** training sessions with **283** staff, across all sectors.

PRIORITY: SUPPORTING LIFE ALONGSIDE CARING

Although rewarding, looking after someone can places a high demand on unpaid carers, meaning that many will have a life that is consumed by taking care of someone else, leaving little time or energy to consider their own needs. Unpaid carers often put their own physical, emotional or psychological well-being behind that of the person they are caring for, which has a detrimental effect on their well-being. Unfortunately due to the pandemic opportunities for respite have been drastically reduced leaving unpaid carers feeling even more isolated **36%** stating that they often feel lonely. more worryingly unpaid carers are rating their satisfaction with their lives, on average as a 4 out of 10 and their anxiety levels as a 6 out of 10.

Although maintaining a balance is vitally important for unpaid carers, unfortunately for many this is simply not the reality. There continues to be definite barriers to carers achieving a work-life balance, many are finding it increasingly difficult to juggle a career and their unpaid caring role. The change to working patterns, due to the pandemic, have benefited some unpaid carers with the ability to work form home where they previously were unable to. The recent State of Caring Wales report highlighted that **21%** of unpaid carers would have had to reduce their hours had they not had the option to work from home. However, **76%** of unpaid carers who are also in employment are still reporting being tired.

Cardiff and Vale Health Board are acutely aware of the difficulties faced by unpaid carers in trying to maintain a life alongside caring. We continue to work alongside third sector and local authorities, amongst others, to enable and support carers. The following section outlines the work that has been undertaken to support life alongside caring.

63%
of unpaid carers in Wales have given up opportunities at work due to caring

33%
of unpaid carers in wales said they need their employer to be more understanding

71%
of unpaid carers in Wales worry about their ability to continue jugging work and their caring role

STAFF UNPAID CARERS

The Carers Lead continues to offer information and advice to the Health Boards staff unpaid carers via email and over the telephone. With the Health Board adapting through the pandemic and offering new ways of working, enquiries around the work life balance policy have reduced.

Over the next year the Carers Lead, along with the Information and Support Centre Manager, will be engaging with the Employee Health and Well-being Team to pilot some staff unpaid carer drop in sessions. The aim of the sessions would be to help staff navigate Health Board policies that will help them to balance work with a caring role, as well as signpost to services in the community that would benefit both them and the person they care for.

EDUCATION PROGRAMME FOR PATIENTS AND CARERS (EPP)

The Health Board's Education Programme for Patients and Unpaid Carers continues to run short online coursed for unpaid carers. Understanding that the pandemic has presented many challenges for unpaid carers over the last two years, they have created a 2.5-hour online workshop focusing on physical and mental wellbeing. Topics covered include;

- Practical ways to create islands of calm in your day
- Mindfulness
- The importance of sleep

These courses are free to unpaid carers and are held approximately four times a year.

The EPP Team has also developed a referral/signposting form that can be used in the community, if a community organisation identifies an unpaid carer and is unsure what support is available. Once EPP team receive the form they can then register the unpaid carer onto one of their courses or signpost to a more relevant service.

VALE OF GLAMORGAN CARERS SUPPORT WORKERS AND CARDIFF CARERS TEAM

The Carer Support Workers in the Vale of Glamorgan and Carer Assessment Workers in Cardiff support carers by undertaking Carers Assessments, for carers over the age of 18, to look at their needs. The Carer Assessment Workers contact the carer to talk about the help the cared for person needs, the type of help the carer is providing and the amount of care they are giving. These discussions help the carer and Carer Support Worker and Carer Assessment Workers identify how the caring role is affecting the carers;

- Health and wellbeing
- Job and work life balance
- Social life and/or potential loneliness and isolation
- and personal life in general.

Depending on the outcome of the carer's assessment the assessors Carer Support Workers are able to signpost the carer to local groups, activities and services to ensure that they are able to continue to have a life alongside the caring role.

CARDIFF
CAERDYDD

VALE of GLAMORGAN
BRO MORGANNWG

PATIENT EXPERINCE SUPPORT WORKERS

During the height of the pandemic the Patient Experience Team engaged with Cardiff University and it was agreed that their Medical and Nursing students could be a great form of support for patients, families, and unpaid carers. The students on placement within the Patient Experience Team undertook tasks including:

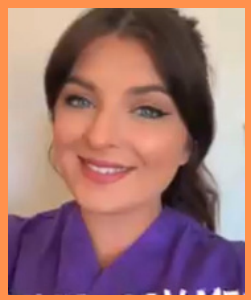
- Contacting next of kin/unpaid carer and providing updates and facilitating virtual visiting. This provided reassurance as the next of kin/unpaid carer could visually seeing the patient. It also provided an option for those who are housebound, immobile or with limited transport to communicate with their loved ones.
- Signposting to other support groups and information. Once the Patient Experience Support worker had linked in with a patient and their family/unpaid carer they were able to support them in a number of ways which included providing information about support service available to them.
- Providing necessities such as pyjamas and clothing. This element of the role was vital in ensuring that patients dignity was maintained and also gave families/unpaid carers comfort and reassurance that their loved one was not left in a hospital gown or dirty clothes when they were not able to visit and bring in these essential items themselves.

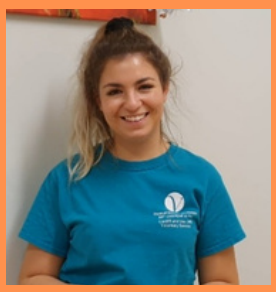
These tasks along with many others helped in reducing pressure on ward staff and aided the continuation of social interaction and engagement with family/unpaid carers.

Realising the importance of this role a bid was placed, by the Patient Experience Team, for funding to be able to continue offering wards the support of our Patient Experience Support Workers via bank (temporary staffing). The Cardiff and Vale Health Charity awarded the funding allowing this vital service to continue throughout the whole of the pandemic.









Between January 2021 and March 2022, PESWs have supported ward staff, patients and their families/friends across the Health Board, with over **1480** recorded contacts over **2200** recorded hours. Although reduced we still have a number of Patient Experience Support Workers who continues to provide support to patients and their relatives/unpaid carers.

Patient Experience Support Worker Feedback

I wanted to write and express my thanks to the Patient Experience Team for this brilliant initiative in these uncertain and what must be very lonely times for patients in hospital who have no means of keeping in touch with family and friends.

Relatives Feedback

Thank you doesn't say enough A palliative patient's family have reported that they appreciated their help and said they made an impact on the patient's stay for the patient and the family.

Ward Staff Feedback

We hope we contributed something during this difficult period for the NHS. Also, we personally gained much experience to take forward for the rest of our careers.

PE Support Worker Feedback

UNPAID CARERS LANYARD SCHEME

Over the last few months Covid-19 restrictions within the community have being fully lifted, however, within a hospital setting there are still some restrictions to visiting to ensure the safety of our patients. Currently all patients are allowed one, on hour, visit a day, but for those with unpaid carer needs the number of visits and length of time can be increased. This visiting plan is agreed in partnership with the patient, Nurse in Charge and the unpaid carer on a case by case basis. In order to support this visiting process and so that staff can easily identify an unpaid carer, and therefore not have to question why they are on the ward, the Patient Experience Team will be rolling out the unpaid carers lanyard scheme.

Unpaid Carers identified by the ward staff, or other professional, will be given a lanyard to wear whilst on our hospital sites which will clearly identify them as unpaid carers. The card is detachable from the lanyard for those unpaid carers who do not wish to wear a 'label', they can place the card in the wallet/purse and show it when required, for example to gain entry to a ward on multiple occasions on one day. The State of Caring Wales reports often highlight that unpaid carers have to keep repeating to staff that they are the persons unpaid carer when attending appointments. In the future we hope that the lanyard scheme can be used in areas such as Out-patients to help to resolve this issue.

BEREAVEMENT CALLS: LIFE AFTER CARING

In response to the isolating nature of the Covid-19 pandemic the Bereavement Lead Nurse developed an ambitious service whereby all next of kin of those who died of Covid-19 in a hospital setting are contacted by telephone. The aim of the call was to provide emotional support, signpost to useful organisations, and to address any queries, where possible, regarding the death of their loved one. Although this service was not set up specifically for unpaid carers it has inadvertently provided support for unpaid carers whose role has come to an end due to the death of the person they care for. The team have been able to provide information on services in the area that are specific to bereaved unpaid carers. In addition it has also helped families where it was the unpaid carer who had passed away, which meant another family member was having to take on the caring role.

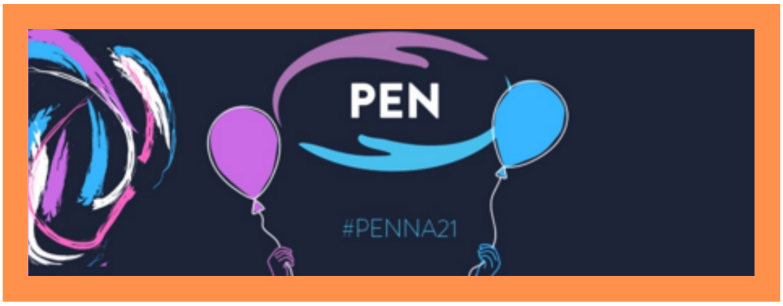
Service Feedback

'Thank you so much for taking the time to think of me, thank you for caring.'

What a fantastic and worthwhile service you are providing

I never thought I would be the type of person to call and ask for counselling, but having spoken to your team I realise that I need support

The team has contacted over **2300** next of kin since March 2020 and the service was runner up in the Patient Experience Network National Award, Support for Caregivers, Friends and Family Category.



YOUNG CARERS

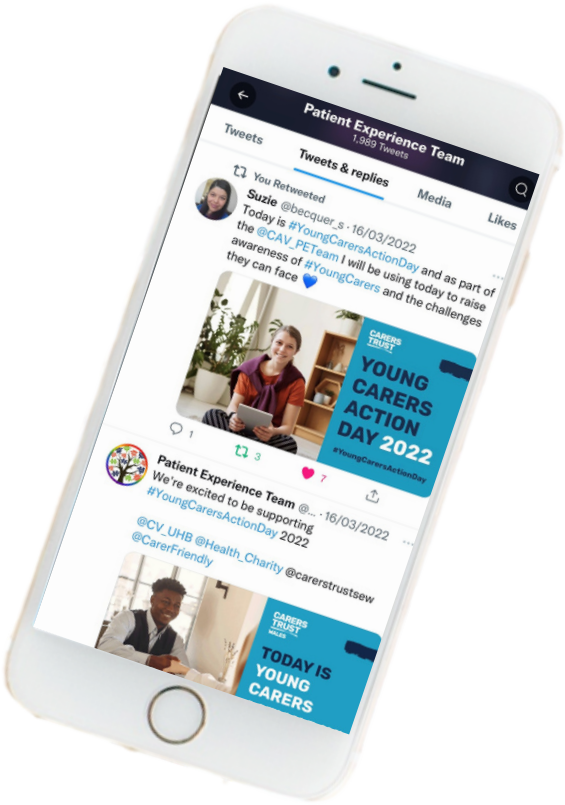
We are committed to continue to build upon the work we have undertaken in previous years to improve the experiences of young carers. Our priorities are built around the consultations we have had, in previous years, with young carers and the feedback that have given us, expressing a lack of awareness of their role. In addition they feel that there is also a lack of support both with practical issues and issues regarding their health and emotional well-being. This feedback is central to all initiatives that we develop to help improve the experience of young carers with in Cardiff and the Vale of Glamorgan.

The 2011 the national census identified 1,579 young carers within Cardiff and Vale of Glamorgan, however, we expect this figure to rise dramatically once the data has been collated for the 2021 national census. We are already aware that current numbers of young carers are underestimated, when compared with other surveys of school children across the UK. In addition with the reported rise in unpaid carers, throughout the pandemic, it is highly likely that a percentage of those will be young carers.

Cardiff and Vale University Health Board and both of the Local Authorities have been working on raising awareness of young carers the roles they undertake and the issues they face. Working with Third Sector partners training has been provided to schools and health colleagues. The following sets out the work being undertaken to strengthen our young carer's agenda across Cardiff and the Vale of Glamorgan.

YOUNG CARER ACTION DAY 2022

In March 2022 Young Carers Action Day was celebrated across Cardiff and the Vale of Glamorgan. Unfortunately due restrictions we were once again unable to hold and event, however, a communications plan was put in place across the Health Board which included raising awareness of young carers via our internet and social media platforms.



YOUNG CARERS ID CARD

During Carers Week 2021 the Young Carers ID Card scheme, funded by Welsh Government, was launched. The aim of the card is to help professionals including doctors, teachers and pharmacists to recognise young carers and support them appropriately. The Young Carers ID Card will provide photo-identification for any young carer aged 18 or under who would like to be part of the scheme.

The YMCA Young Carers Team, are facilitating the creation and delivery of the cards, working with representatives from Health, Social Services and Education from both Local Authorities. Due to Covid, the Team has been unable to raise awareness of the Young Carers ID Card as much as they would have hoped, however, with restrictions easing the team will be looking to engage with schools to undertake assemblies to help increase the numbers of cards in use.

Since the launch around **100** cards have been distributed across Cardiff and The Vale, however, early feedback from young carers in Secondary Schools has indicated that they would prefer an app to a card.

Future plans for the ID Card are to introduce benefits for carers such as discounts in leisure facilities, travel and shops. There are also discussions with partners in Pharmacy and Primary Care to look at how the card could be used to support cares in Health CARE Settings.

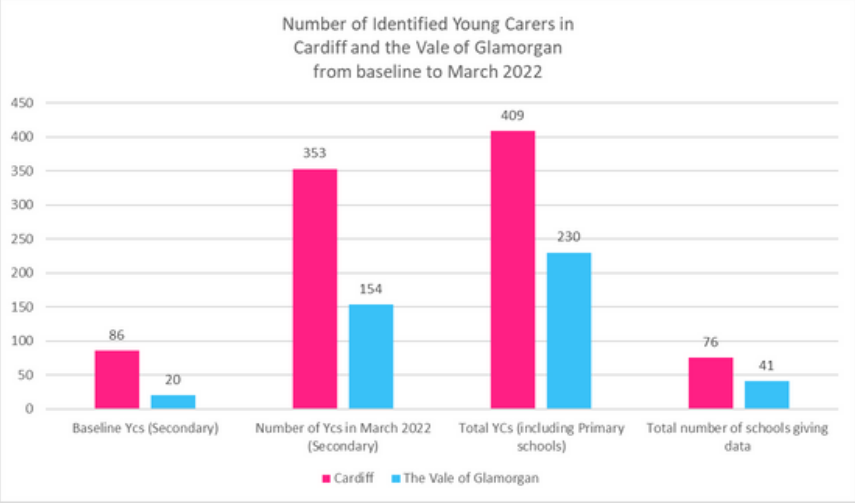
YOUNG CARERS IN SCHOOLS AWARD

The Care Collective (formally Carers Trust South East Wales) Young Carers in Schools Programme provides schools with the tools and resources to support young carers, giving them the same access to education, opportunities and future life chances as their peers. Schools are asked to produce, collate and submit evidence around five key themes which is reviewed by the Peer Review Panel.

There are three stages of the Young Carers in Schools Programme:

The Young Carers in Schools programme has reported that the continued impact of COVID-19 has had a affect on the running of the programme. Schools are experiencing numerous staff shortages, and are struggling to engage with the programme because of competing priorities. This has resulted in some schools have decided to delay progressing with the programme due to their current responsibilities.

However, despite the challenges, this year the team has seen an increase in participation, **17** of the 18 Secondary schools in Cardiff (**94%**) are now participating in the programme and the Vale of Glamorgan have maintained **100%** participation. The scheme has also been rolled out to Primary schools and currently Three primaries across Cardiff and the Vale of Glamorgan are engaged. This year has also seen **2** schools achieve 'The Basics' award, **1** school achieve 'Beyond the Basics' and **5** schools achieve 'Best Practice' across Cardiff and the Vale of Glamorgan. In addition there continues to be an increase in the numbers of young carers identified in schools. At baseline the number of identified young carers in Cardiff and the Vale of Glamorgan Secondary schools was **106**, to date this has increased to **507**.



This year the team have updated their 'Young Carers: Identifying Us' training for school staff. This was in consultation with young carers and listening to feedback from staff, provided after previous sessions. This financial year, approximately **47** staff have taken part in the 'Young Carers: Identifying us' virtual staff training events in Cardiff and the Vale of Glamorgan. Feedback from the training saw **100%** of participants agreeing that it was beneficial and **89%** stating that it had increased their level of confidence to identify a young carer.

EXPENDITURE AND FINANCIAL POSITION

The Cardiff & Vale Partnership was allocated funding of £144,000. The table below illustrates how the funding was utilised.

Work Stream	Priorities Addressed
Carer Friendly Scheme	• Identify and recognise carers • Providing information, advice and assistance
Young Carers in Schools Award	• Identify and recognise carers • Supporting life alongside caring • Providing information, advice and assistance
Hospital Discharge Project	• Identify and recognise carers • Supporting carers through hospital discharge • Providing information, advice and assistance
Carers Gateway	• Identify and recognise carers • Supporting life alongside caring • Providing information, advice and assistance

CONCLUSION

This report illustrates the partnership work being undertaken during 2021/22, which has been over seen by the Cardiff and Vale working group, in line with the three national priorities set out in 2018. It highlights new initiatives as well as ongoing progress in multiple areas supporting young carers as well as adult and working carers. For more information on any of the work set out in the report please email Pe.cav@wales.nhs.uk

Report Title:	Quality, Safety and Experience information centres annual report			Agenda Item:	6
Meeting:	**QUALITY, SAFETY& EXPERIENCE COMMITTEE- Special Meeting**	Public	✓	Meeting Date:	11/10/22
		Private			
Status	Assurance	✓	Approval		Information
Lead Executive:	Executive Nurse Director				
Report Author	Assistant Director of Patient Experience				

Background and current situation:

The annual report outlines the activities in our information centres. The report demonstrated the adaptations to the pandemic and the future plans

We have also provided some information about the history and development of the centres

We have as part of Patient Experience commenced the management of the Bute town multi-cultural resource centre and the staff who work there this will be our first community-based centre and we hope to develop more and pop up centres in many of our diverse communities

Recommendations:

The Committee is requested to:

a) note the report.

Link to Strategic Objectives of Shaping our Future Wellbeing:
Please tick as relevant

1. Reduce health inequalities	✓	6. Have a planned care system where demand and capacity are in balance	
2. Deliver outcomes that matter to people	✓	7. Be a great place to work and learn	
3. All take responsibility for improving our health and wellbeing		8. Work better together with partners to deliver care and support across care sectors, making best use of our people and technology	
4. Offer services that deliver the population health our citizens are entitled to expect	✓	9. Reduce harm, waste and variation sustainably making best use of the resources available to us	✓
5. Have an unplanned (emergency) care system that provides the right care, in the right place, first time		10. Excel at teaching, research, innovation and improvement and provide an environment where innovation thrives	

Five Ways of Working (Sustainable Development Principles) considered
Please tick as relevant

Prevention		Long term		Integration		Collaboration	✓	Involvement	✓

Impact Assessment:
Please state yes or no for each category. If yes please provide further details.

Risk no

Safety: no

Financial: no
Workforce: Yes
We encourage use of the centers for work-based session such as immunization and citizens advice which are open to our staff
Legal: Yes
We need to adhere to the relevant legislation
Reputational: No
Socio Economic: Yes
Consideration of socio-economic disadvantage needs to be further explored through interrogation of the quality indicators to the level of low super output areas of social deprivation in comparison to areas of affluence
Equality and Health: Yes
When reviewed in detail it should be considered if any reports demonstrate equality and health inequities
Decarbonisation: Yes/No

Approval/Scrutiny Route:	
Committee/Group/Exec	Date:

GIG CYMRU NHS WALES

Bwrdd Iechyd Prifysgol Caerdydd a'r Fro

Cardiff and Vale University Health Board

Information and Support Centres

Annual Report 2022

Celebrating 10 years

"The journey so far...."

Contents

Introduction

This annual report celebrates the 10 year anniversary of the opening of the **Macmillan Information and Support Centre** in the Concourse area of the University Hospital of Wales. It provides a snapshot of the developments in the intervening 10 years and provides data on the financial year April 2021 to March 2022.

Background

In 2011, Cardiff and Vale University Health Board (UHB) worked in partnership with Macmillan Cancer Support to open the Macmillan Information and Support Centre in Concourse, University Hospital of Wales (UHW), Cardiff.

The Centre was opened on 16th April 2012 and in the first two weeks of opening, 233 visitors came to the Centre with a multitude of questions relating to cancer and health promotion.

On the 29th November 2012 the Centre was officially opened by Lesley Griffiths AM, Minister for Health and Social Services. Maria Battle, Chair UHB, Susan Morris, General Manager for Macmillan in Wales, Ruth Walker, Executive Nurse Director and service users, providers and members of the Macmillan Steering Group also attended.

Pictured (L-R) Maria Battle, Chair, Cardiff and Vale UHB, Lesley Griffiths AM, Minister for Health and Social Services Susan Morris, General Manager, Macmillan in Wales and Sue Llewellyn, Macmillan Information and Support Facilitator.

The overall aims of the service were:

- to capture the ‘foot-fall’ of the patient and family/carer population coming through the hospital that were in receipt of cancer care and/or treatments in order to provide them with relevant, accurate, timely information in a non-threatening environment.
- to work with the Cancer Services Group and link with the Cancer Leads to co-ordinate and make relevant the information that is being offered to patients and their families within the UHB.
- to standardise the quality of the information that is being delivered to patients and their families throughout the UHB in-patient area.
- to support all professionals involved in cancer care and co-ordinate their efforts to ensure appropriate relevant communication.
- to be able to provide information and support to patients and their families attending hospital as out-patients.
- to provide information and support for those visiting in-patients with a cancer diagnosis.
- to make links with external sources of support in order to be able to signpost patients to support and resources in their local areas.
- to work across both acute hospitals to ensure the information resource in University Hospital Llandough (UHL) is up-to-standard and to consider outreach to this hospital if a need for this is identified.
- to support referrals from other professionals within the UHB.
- to determine the most effective times to provide information and support related to the out-patient clinics and visiting hours.
- to develop links with Multi Disciplinary Teams and Cancer Leads to ensure the co-ordination and feedback of concerns and issues.
- raise the profile of the service to outside support agencies, the general public and the Welsh Assembly,
- to continually audit the information and support provided and to improve the service based on this - including undertaking Patient Satisfaction Surveys.
- to evaluate the service in order to make a case for sustainability,
- to receive support and direction from a multi-disciplinary ‘steering group’ which will meet quarterly and report annually.
- to ensure the continued professional developmental needs of the post holder are sustained in order that s/he can deliver a first class service.
- to ensure the physical environment in which the service is located is maintained according to Macmillan best practice and quality standards for information and support environments; to also ensure all signage and awareness raising materials are of good quality and visible.
- to identify ways to develop and sustain the service e.g utilising volunteers.

During the first year, the Facilitator Sue Llewellyn attended various events to raise the profile of the Centre including the Eisteddfod, the Annual Minority Ethnic Communities Health Fair and the Prostate Cancer Support Group.

In the first year over 926 visitors were seen by the Facilitator between April and July 2012. In the second year this increased to over 2,564 visitors.

The visitors to the Centre continued to grow with an average 2,500 visitors each year and 30,000 booklets reorderded. General cancer information continued to be the most asked for information. Most enquiries came from those recently diagnosed or undergoing treatment.

Developments

Building on the success of the Centre in UHW, the UHB worked with the local authority and third sector partners and in May 2014 the Information and Support Centre in the University Hospital Llandough (UHL) was opened. In March 2016, the Centre moved to its current location in the newly built Plaza on the main corridor into the hospital.

In August 2016 the Patient Experience Team opened the Information and Support Centre in Barry Hospital. The Centre is small in comparison to the others, but has information on a range of health conditions relating to the departments at Barry Hospital – mental health, chronic conditions, dementia as well as health promotion and a section for carers.

At the end of February 2017, Sarah Davies took up the post of Facilitator. During her first year, she attended a number of events to raise the profile of the Centres, including Cardiff Health and Social Care Network Meetings, Cancer and Older People's Advocacy Service Steering Group and the Vale Health Social Care and Wellbeing Network Meetings.

During the following few years, more volunteers were recruited to support the Centres and a wider range of printed materials from a diverse range of organisations was provided and put on display throughout the hospital. The number of leaflets and booklets peaked in 2018-2019 with nearly 43,000 leaflets and booklets ordered.

The visitors numbers continued to rise, peaking in 2021-2022 with over 21,000 visitors. Requests for directions to clinics and departments have increased with more volunteers visible in the Centres to help visitors.

Information enquiry numbers were down slightly in 2021-2022 with Covid-19 pandemic still restricting the number of people visiting the hospitals but cancer remained the top topic for enquiries.

The Covid-19 Pandemic

In March 2020, the Centres closed for face-to-face visitors due to the Covid-19 pandemic and all leaflet and booklets were removed from the Centres and clinics. Support for patients carers and families continued by telephone and email throughout the Covid-19 pandemic, although numbers were low.

The Centres became the drop-off point for donations from other organisations and members of the public who wanted to give back to the NHS during a very difficult time. The Centres took in donatations of toiletries, clothes and activity books and these were distributed to the wards by the Patient Experience Team.

With visiting restricted in the hospitals, a **Clothes Drop-off and Collection Service** was set up and ran from the Information and Support Centres in UHW and UHL. Staff from Patient Experience Team, supported by a team of 41 Hospital Runner Volunteers provided an invaluable service to families and friends. The volunteers also took time to listen to relatives concerns and signposted them to staff if they needed additional

support or advice. The service ran from October 2020-May 2021 and the volunteers provided 929 hours of cover. During this time the volunteers took property to 2,259 patients and brought back dirty washing from 1,237 patients. They walked over 2 million steps!

During the Covid-19 pandemic, the Facilitator was responsible for the repatriation of patient property to families whose relatives had passed away in hospital. Over 400 families were contacted and property was collected from the Centres. The Facilitator also made telephone calls to bereaved families and supported the Bereavement Lead Nurse and her team.

As restrictions were slowly lifted, the Centres gradually reopened. Leaflets and booklets returned to the shelves and more people started dropping into the Centres for information and support.

The Information Centre at Barry Hospital was the last to reopen due to its small size making social distancing difficult. This reopened in November 2021.

A relative was dropping off clothes and essential items for his brother during the Covid-19 pandemic. He explained that his brother had been very fit and healthy until recently but had suddenly become paralysed from the waist down and was unable to walk. All the family were struggling to cope with his sudden disability. The Facilitator signposted them to support organisations and a few weeks later he came back to say thank you for the support they had been given. His brother was being transferred to another hospital to continue his recovery but the family were all grateful for the support they had received.

The Facilitator was contacted by a staff member from the Teenage Cancer Trust. A young lady was due to be discharged to a hostel and was still waiting for her benefits to come through. The Facilitator was able to issue her with a Foodbank voucher and also supplied her with a stock of essential toiletries, sanitary products and warm clothes. She was very grateful as she only had nightwear and a few items of personal possessions and did not know where she would be able to get food from when she left hospital.

A staff member visited the Macmillan Information and Support Centre to ask for help with a patient on their ward. The patient had been diagnosed with breast cancer but was not coping too well. The Facilitator visited the patient and made a referral to the Macmillan Buddy Service for support when she was discharged home. A visit from a hospital Chaplain was also arranged and they were able to support her during her time in hospital. The patient was discharged home and called in a few weeks later to say her treatment plan was going well and she was finding the calls from the Macmillan Buddy helpful. She thanked me for the support she had received.

Since 2017, the Facilitator has been successful in applying to Macmillan grants for patients. The total amount awarded to cancer patients so far is.....

£11,939

citizens advice

Citizen's Advice started providing a drop in session in the Quiet Room, UHW, in June 2012. They provide free confidential, impartial information to patients, visitors and staff. The service was extended to UHL and Barry Hospital continued until March 2020 when the Covid-19 pandemic closed all face to face services. Citizen's Advice continued to provide online and telephone advice and are planning to return to face to face sessions in 2022/23.

Cruse Bereavement Support

Cruse Bereavement Support started meeting in the Quiet Room in 2012 a few evenings a week. This service continued until March 2020 when the Covid-19 pandemic closed all face to face services.They continue to support clients online.

Occupational Health Team

The Occupational Health Team started using with Macmillan Information Centre in 2014 to vaccinate staff and raise awareness of the importance of flu immunisation. They continue to base themselves in the Centre as it is a good place to engage with staff on their way into work, during their lunch break and on their way home. In Autumn 2018 this was extended to the Information Centre at UHL. During the Covornavirus pandemic, the Occupational Health Team continued to use the Centres, immunising staff against flu and Covid-19.

tenovus cancer care gofal canser

The relationship with Tenovus commenced December 2013 at UHW with a Benefits Adviser from Tenovus on-site providing advice about benefits and grants to those affected by cancer. This service has grown over the years and they have supported hundreds of patients. The service continued until March 2020 when the pandemic closed all face-to-face services. Tenovus continued to support cancer patients remotely and this service continues to today. The Facilitator refers people affected by cancer to them on a regular basis.

Other partners:

Asbestos Awareness and Support Cymru
Brain Tumour Support
Cardiff and Vale Credit Union
Cardiff County Council
Dinas Powys Voluntary Concern
Foodbank
Maggie Centre
Recovery Cymru
Relate Counselling Services
Vale of Glamorgan Council
Versus Arthritis

Quality Standards

The **Macmillan Quality Environment Mark** (MQEM) was awarded to the Macmillan Information and Support Centre, UHW for the first time in August 2013. It is a detailed quality framework used for assessing whether cancer care environments meet the standards required by people living with cancer. In meeting the MQEM standards, the Information and Support Centres are demonstrating to users that the environment is: welcoming and accessible to all; respectful of people's privacy and dignity; supportive to users' comfort and well-being; giving choice and control to people using your service; and listening to the voice of the user.

The standard is reviewed every three years and the Centre continues to meet these standards. The next review will take place in August 2022. In 2019, the standard was extended the the Information and Support Centre in Barry Hospital and University Hospital Llandough and they were both awarded the quality mark in August 2019.

The Centres have also achieved **Macmillan Quality in Information and Support Services Standards**©, awarded in February 2019, the Macmillan Information and Support Centre Facilitator achieved the **Macmillan Volunteering Quality Standards**© in August 2019 demonstrating the key skills and competencies required for effective volunteer management.

In 2021, the Patient Experience Team won the “Team of the Year” award in the **Patient Experience Network National Awards**. The awards recognise best practice in patient experience across all facets of health and social care in the UK. The Team of the Year category is to recognise teams who have made a difference to their patients’ experience. This may be due to actions they have taken as a team, exemplary team work or through implementing or supporting a patient experience initiative through cross-team working. Listen to their winning entry presented by Angela Hughes, Assistant Director of Patient Experience highlighting the work of the team
https://www.youtube.com/watch?v=azoL7-RTarE

The three Information and Support Centres were each awarded the **Bronze "Carer Friendly Accreditation"** in June 2019. The Carer Friendly Accreditation scheme aims to improve, share and recognise support for carers in health and social care service areas. All three Centres were also awarded the Silver accreditation in May 2020.

Volunteers

The Facilitator has worked with the UHB Voluntary Services Manager since 2012 to recruit volunteers to help in the Centres. The number of volunteers have grown over the years with a significant increase during the Covid-19 pandemic. With many people on furlough and people wanting to support the NHS, the volunteering agenda grew. This included the number of volunteers in the Information and Support Centres. At the end of March 2022 there were 26 volunteers supporting the Information and Support Centres.

During the past 10 years, volunteers have been awarded a number of awards including Volunteer of the Year award in the **Cardiff and Vale UHB Staff Recognition Awards** twice and highly commended in the national **Helpforce Champions Awards** twice!.

Thank you for your speedy reply

Thank you for this information. This is really helpful.

Thank you for the support I had last week when I was upset following an appointment in the Breast Centre. You helped me so much as I was in a state.

Thankyou very much for taking the time to send this through to me.

Thank you so much for your help. Every hospital needs a Sarah.

Saunders,Nathan
10/10/2022 23:47:08

Raising awareness of the Centres has always been an important role for staff and volunteers. Here are some highlights from the past 10 years:

In 2015, Eleri Sion from BBC Radio Wales interviewed the Facilitator and a volunteer in the Macmillan Information and Support Centre about their role in the hospital. The BBC returned for the NHS 70th anniversary celebrations in 2018, when Wynne Evans broadcasted his morning show live from the Centre. The Facilitator and a volunteer from the Centre were interviewed live on air.

In 2019, the Macmillan Information and Support Centre Facilitator was featured in a Christmas story about a former cancer patient from Cardiff and Vale UHB, who surprised the Macmillan professional to say thank you for supporting her last year by dropping off Christmas presents for her three children when she was on statutory sick pay. Macmillan captured the surprise on video which was viewed over 31.8k times.

Local and national events

The Facilitator has been supporting the Minority Ethnic Communities Health Fair since 2014.

To coincide with International Older Persons day (2017) the Facilitator arranged an event in the Boardroom at University Hospital Llandough in partnership with Glamorgan Voluntary Services and Cardiff Third Sector Council.

The Facilitator has supported the Macmillan Coffee Mornings over the past 10 years including hosting a coffee morning in the Centre at UHL in 2019 raising £124.00.

A display for International Men's Day (2018) at Welsh Government offices in Cathays Park.

The Facilitator presented at the Vale Health, Social Care and Wellbeing Network in October 2018, highlighting the work of the Patient Experience Team and continues to be part of this network.

Presentations have included:

Cardiff and Vale University Health Board training event – **Skills to Manage**. This was an opportunity to talk to middle managers and tell them about the Information and Support Centres and how they can support them in their role.

The Facilitator has supported the Carers Lead presenting at all UHB staff induction sessions raising awareness of unpaid carers and the support available to staff from the Centres and other third sector organisations.

The Facilitator has have given a number of short presentations about the Centres at the Macmillan HOPE courses in Cardiff.

Other presentations include a health information session at the Age Connects Shop in Barry to promote the Centres.

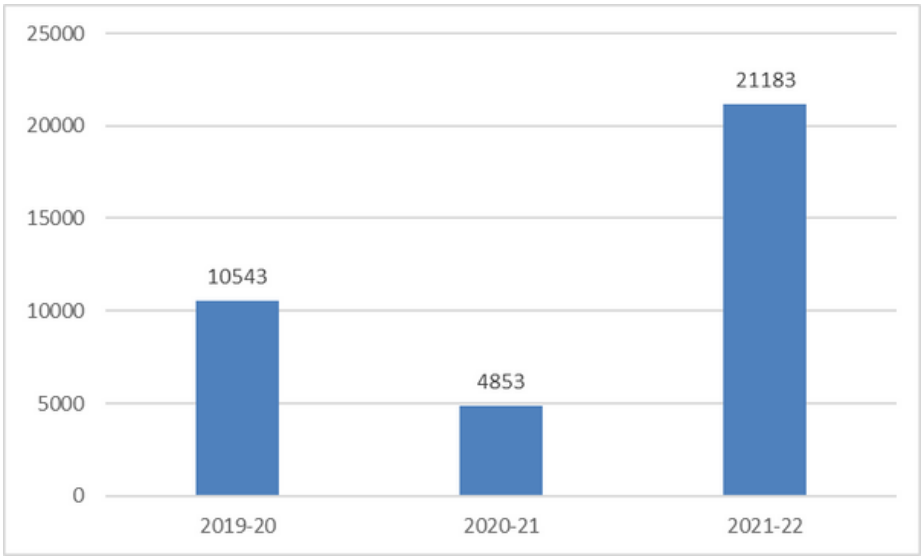
Groups

The volunteer-led Knit and Natter Group, set up in June 2017, continued to meet weekly in the Centre at UHL until the Covid-19 Pandemic stopped all face to face groups. This lively group raised the profile of the Centre by being a focal for patients, staff and visitors and welcomed hundreds of visitors during their weekly meet-up.

The Book Cwtch was launched in 2018 following a successful bid for funding from The Health Charity. It has continued to remain popular with patients, staff and visitors particularly during the Covid-19 Pandemic.

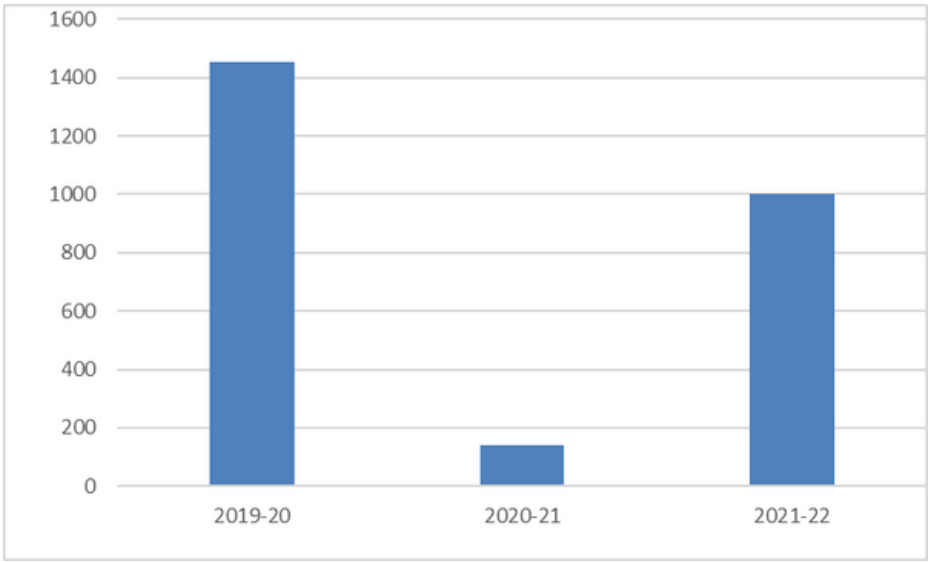
Number of contacts in the Centres

This graph illustrates the number of contacts made whilst the Information and Support Centres were staffed by the Facilitator and volunteers. The increase in 2021-22 reflects the increase in volunteers supporting the Facilitator.



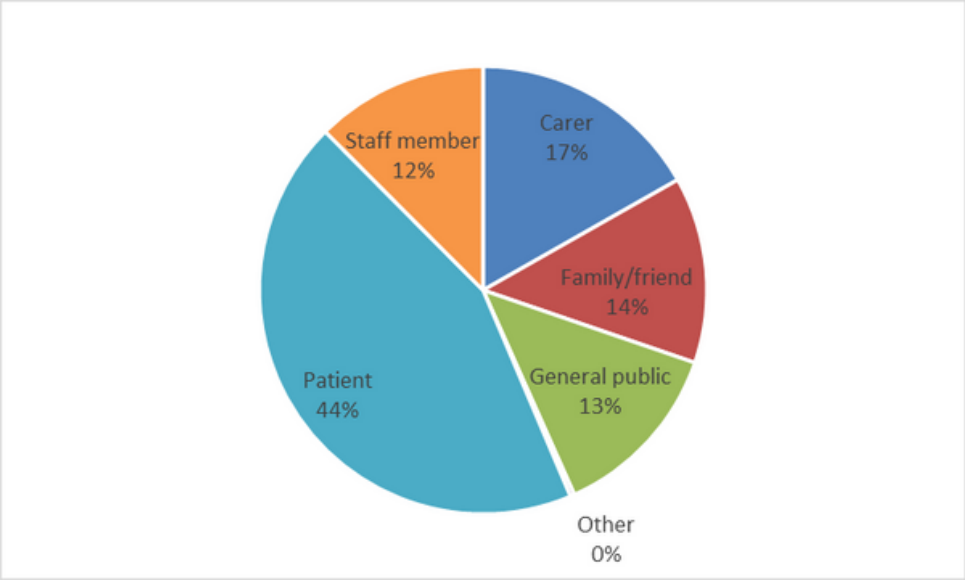
Number of enquiries in the Centres

The majority of enquiries are opportunist, from people who are passing the Information and Support Centres with others signposted by staff, family or friends.



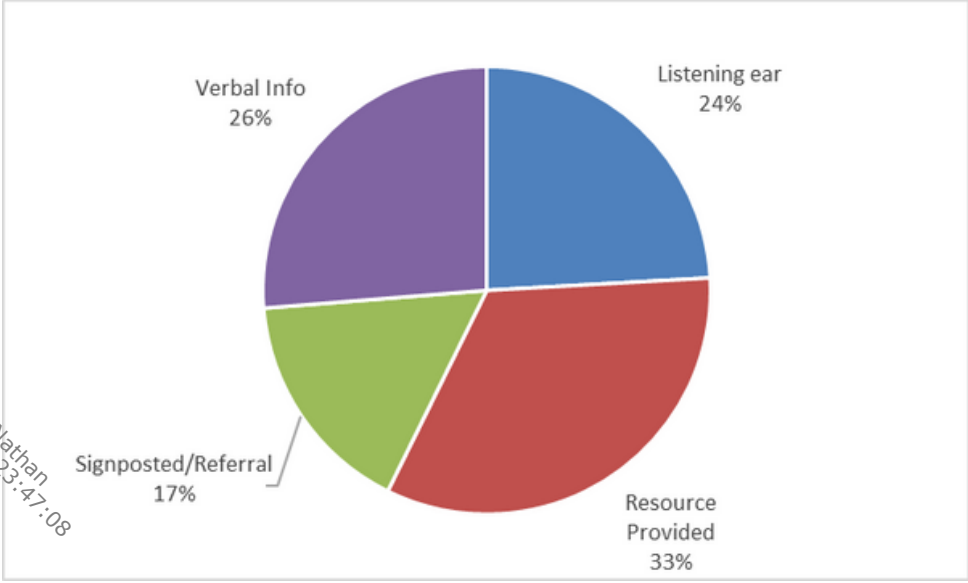
Type of service user in the Centres

The majority of enquiries come from patients visiting the Centres.



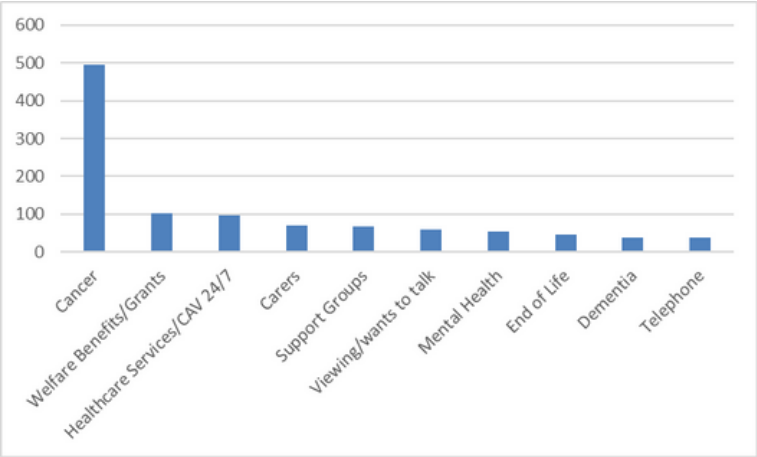
Actions or outputs in the Centres

The people making enquiries are provided with information leaflets and booklets and signposted to other services such as Tenovus, Macmillan or local support groups.



Topic of enquiry

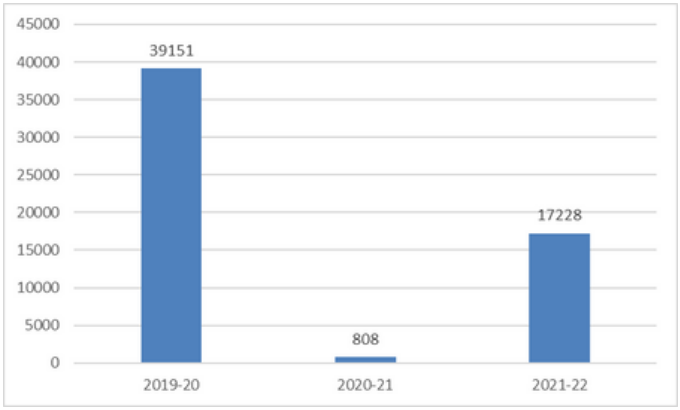
The majority of enquiries are from people living with cancer and the Centres gives them an opportunity to talk about their cancer journey and their concerns. These conversations are backed up with information.



Number of resources ordered in the Centres

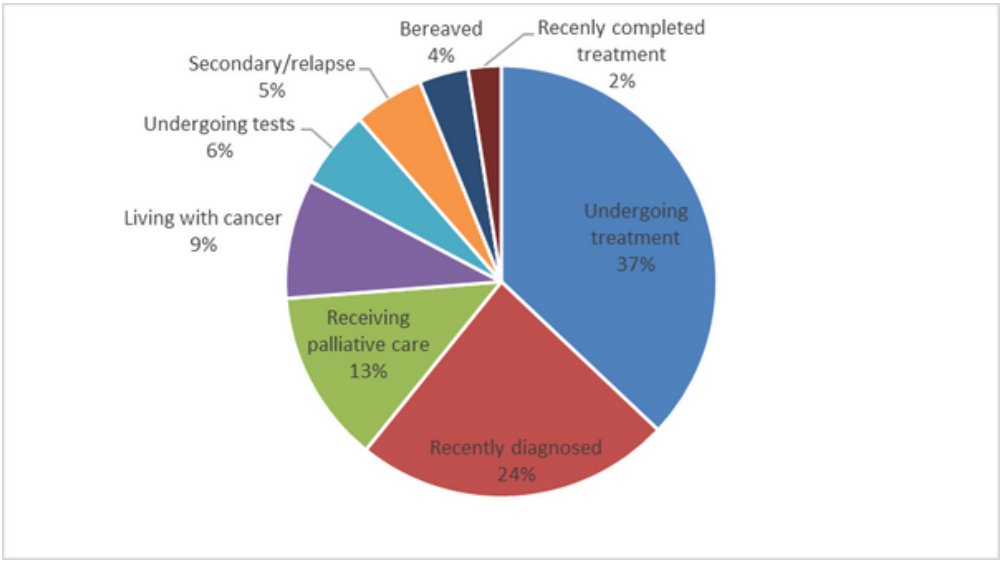
The leaflets and booklets on display in each of the Centres are based on the services offered at each hospital site. They are also based on feedback received from visitors to the Centres. All of the leaflets and resources are sourced and provided free of charge.

Prior to the Covid-19 pandmic, the Facilitator and volunteers kept leaflet racks across the hospitals up to date and stocked. Since restrictions have lifted, some leaflet racks are now stocked but this is still limited due to restricted access in areas of the hospitals.



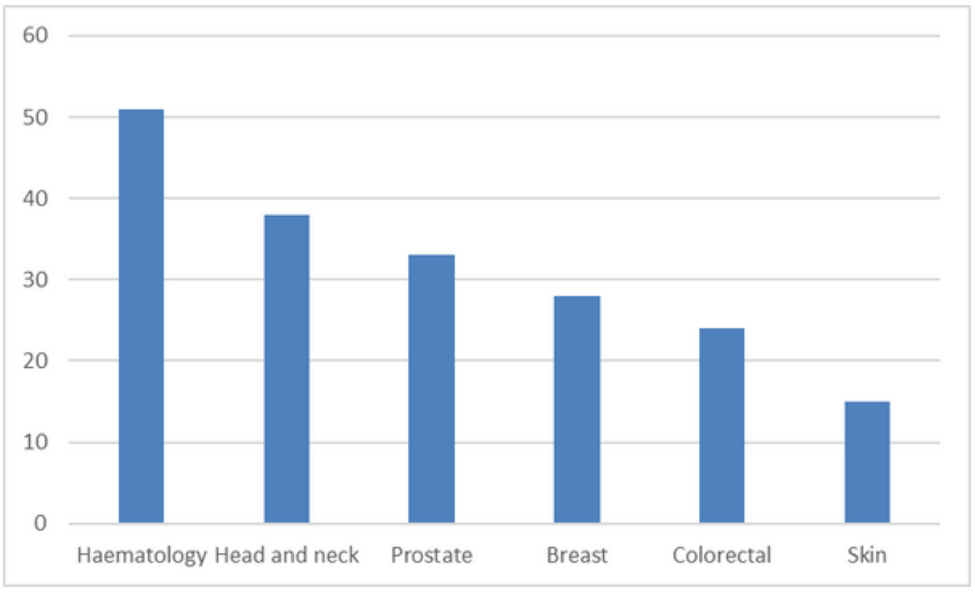
Stage of Cancer Pathway

The majority of enquiries come from people who have had a recent cancer diagnosis or are undergoing treatment.

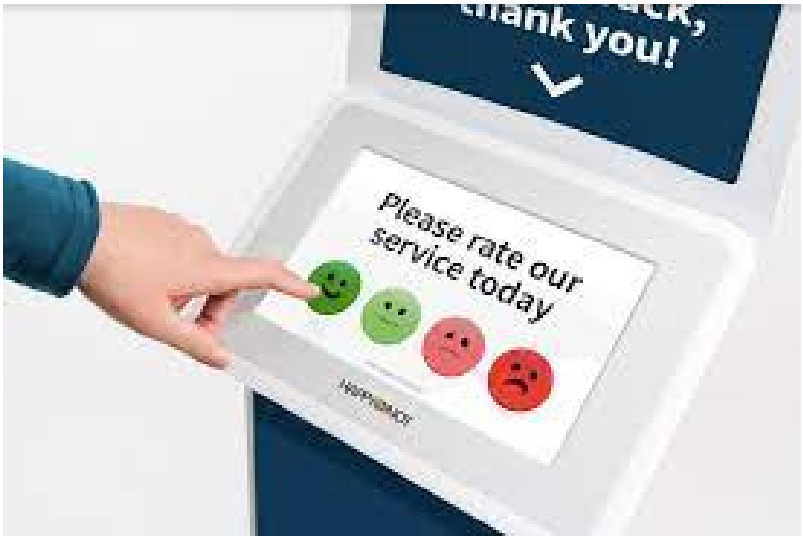


Cancer Type

The Haematological Cancer Service in the UHB is the largest in Wales and one of the busiest in the UK. This is reflected in the most asked for cancer information.



Since the Covid-19 pandemic, the way we have provided servies has changed. We are engaging with patients, visitors and staff on how we can move forward with the services in the Centres and will install feedback terminals and a questionnaire for visitors.



We will engage with our third sector partners to re-establish face to face services.

We will reapply for the Macmillan Environment Quality Mark.

Following feedback from visitors, an appointment system will be trialled. People will be able to book a face to face or a virtual appointment with the Facilitator.

Information and Support Centres, Cardiff and Vale University Health Board 10 years in Pictures

2012

Macmillan Information and Support Centre in Concourse, University Hospital of Wales opened

2013

Macmillan Quality Envionment Mark first awarded

2014

Information and Support Centre, University Hospital Llandough opened

2015

BBC Radio Wales Interview with Eleri Sion, Louisa Sham, Volunteer and Sue Llewellyn, Facilitator

2016

Information and Support Centre, Barry Hospital opened

2017

Sarah Davies, Information and Support Centre Facilitator took up post

2018

Wynne Evans from BBC Radio Wales broadcasted his morning show live from the Macmillan Information and Support Centre to coincide with the NHS 70th anniversary celebrations.

2019

Sarah Davies, Facilitator featured in a Macmillan Christmas story about a cancer patient, who called in to say thank you for supporting her last Christmas by dropping off presents for her children.

2020

Covid-19 Pandemic

At the end of March 2020 all the leaflets were removed from the Information and Support Centres and face to face contact was stopped. Volunteers were not allowed to come into the hospitals and staff worked from home when possible.

2021

The Information and Support Centres in UHW were repurposed and ran other essential services including the Clothes Drop Off and Collection service.

2022

With a few adjustments the Centres are back open.