Meeting Date	**21st February 2019**	**Agenda Item**	**6.9**
Report Title	**NHS Wales Delivery Unit Report Review of Impact of Long Waits for Planned Care on Patients**		
Report Author	Darren Griffiths, Associate Director of Performance		
Report Sponsor	Darren Griffiths, Associate Director of Performance		
Presented by	Darren Griffiths, Associate Director of Performance		
Freedom of Information	Open		
Purpose of the Report	The purpose of this report is to inform the Quality and Safety Committee of the key findings arising from the NHS Wales Delivery Unit (DU) review of the longest waiting patients on the Health Board's waiting list. The review report was formally received by the Health Board on 28th January 2019. This report is therefore an account of the content of the review. An action plan to address the recommendations will be developed and this will be shared with future quality and safety committee meetings for assurance.		
Key Issues	This report sets out the key findings from the review. A summary of the detail of the review is in the body of this report and the full review which is attached as **Appendix A**. The key messages are that patients are waiting too long for surgery in some specialties which results, in some cases, in poor experience, possible increased risk of harm and poor communication with patients. Processes for the monitoring of, and connectivity of, incident reporting, complaints, waiting times and risk could be better aligned. Some aspects of good practice were noted in terms of consent processes which could be rolled out. 12 recommendations are identified in the report which the Health Board accepts and will be used to develop a detailed action plan to address the findings of the review.		

Specific Action Required *(please ✓one only)*	Information	Discussion	Assurance	Approval
	✓			
Recommendations	Members are asked to: - • **NOTE** the content of the review report • **NOTE** that an action plan will be developed to address the recommendations within the review • **NOTE** that future Quality and Safety Committee meetings will receive updates on progress against the plan • **NOTE** that the report will also be presented to audit Committee at its March 2019 meeting			

NHS WALES DELIVERY UNIT REPORT

REVIEW OF IMPACT OF LONG WAITS FOR PLANNED CARE ON PATIENTS

1. INTRODUCTION

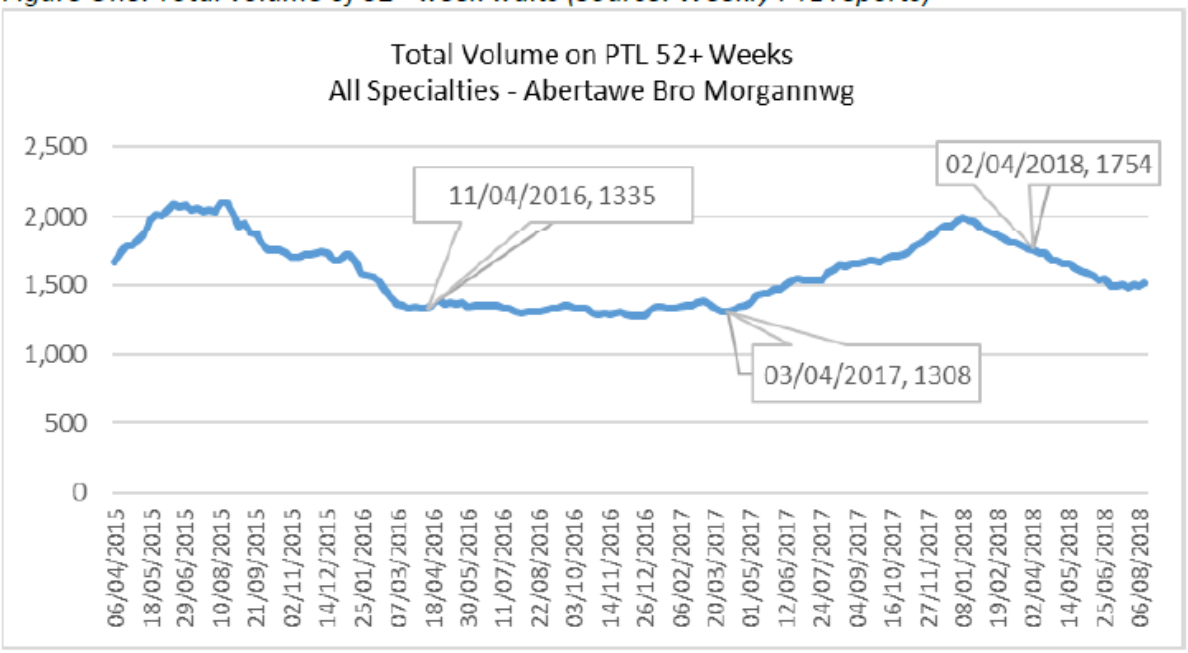
In response to concern about increasing numbers of patients waiting 52 or more weeks for planned care treatment, for whom the impact was not widely understood, the NHS Wales Delivery Unit (DU) undertook a Wales-wide review of long waits for planned care. The Health Board participated fully in this review. This report sets out the principal findings of the review with the full DU report attached (**Appendix A**).

Given the timing of the receipt of the DU report, an action plan is yet to be developed. This report is therefore an account of the content of the review and a presentation of the key messages contained therein. An action plan to address the recommendations will be developed and this will be shared with future quality and safety committee meetings for assurance.

2. BACKGROUND

The chart below sets out the numbers of patients waiting over 52 weeks for the Health Board since April 2015 and is extracted from the DU report.

Figure One: Total volume of 52+ week waits (Source: Weekly PTL reports)



At the end January 2019 this figure currently stands at 1,349.

The combined positon across Wales in terms of long waiting times was the trigger for the commencement of the All Wales work by the DU.

The review work commenced in September 2017 and considered three sources of evidence to enable the findings to be developed.

1) Case notes were reviewed for a sample of these patients
2) Patient feedback was received; and
3) Discussions were held with Health Board staff

The report sought to assess the impact of long waits for patients in terms of potential harm and adverse outcomes and to seek assurance that organisations have robust processes in place to safeguard patients and to address the issues underlying extended waits for treatment.

The Health Board received the review report on 28th January 2019. The review focussed on the examination of waiting lists with patients waiting greater than 52 weeks at the end of September 2017 with the fieldwork and associated analysis being completed over the following 14 months.

3. GOVERNANCE AND RISK ISSUES

The key messages from the report are set out over seven areas. Set out below are the seven areas and a summarised view of the message contained within each.

1) **Patient impact** – generally long waiting patients were not found to be at any higher risk of an emergency attendance or inpatient admission than those waiting less than 52 weeks, however some evidence of harm was noted (page 2).
2) **Areas of greatest concern** – complex patients and patients on multiple pathway had poor experiences (page 2).
3) **Management of clinical risk** – risk management processes were generally reactive and communication gaps over 12 months were noted (page 3).
4) **Resource utilisation** – long waits resulted in repeated investigations and multiple cancellations of surgery (page 3).
5) **Governance** – clear performance management and quality and safety structures were demonstrated. However, connectivity between complaints, lengths of wait and incident reporting could be improved (page 3)
6) **Improvement action** – stronger risk management whilst patients are experiencing long waits (which the Health Board has plans to address) would be beneficial (page 3).
7) **Notable practice** – enhanced consent process may have wider applicability for a range of specialties (page3).

As a result of these key messages the review identified 14 key recommendations and these are set out below as they appear in the final report attached.

It is recommended that the Health Board: -

1) Implements a proactive review of patients at clinically determined points during the pathway, and at 52-weeks as a minimum. Harm review literature from NHS England provides an evidence base for the value of undertaking such views to identify whether patients have experienced any harm/adverse impacts. The DU is proposing Wales- wide debate to construct and implement a proactive harm review process.

2) Implements a mortality review process for patients who die after a wait greater than 36 weeks for planned treatment, to seek assurance that the delayed treatment was not a contributory factor to avoidable harm.

3) Seeks to install a PAS system alert for patients with more than one RTT pathway and reviews processes to ensure that a discussion is held between the multi-disciplinary teams to manage interdependencies in the patient's care and to support the patient to prioritise treatment.
4) Reviews processes for primary and secondary care collaboration for complex patients on more than one pathway.
5) Reviews its communication and engagement processes for patients on RTT pathways, with a particular focus on ensuring that contacts and appointments with patients facilitate patients' feedback, and patients are made aware of how to contact the Health Board in the event of a change in their condition/symptoms. The national work on patient reported outcome measures and patient reported experience measures provides a framework for some planned care pathways; there is scope for the Health Board to expand its use of this framework.
6) Reviews how concerns data (including incidents and near misses) for long waits is recorded and used at quality & safety meetings and how widely this is disseminated and informs planning for improvement.
7) Reviews the use of local risk managements systems to ensure that incident and complaint data can be identified for the same episode of care.
8) Raises awareness amongst staff of the importance of reporting near misses and early identification of acts or omissions along the patient's pathway to facilitate learning to prevent similar situations from arising.
9) Reviews the use of concerns data to identify trends and share learning for a range of specialties across the Health Board.
10) Reviews the criteria for acceptance of referrals and listing for treatments with a high volume of ROTT, with a particular focus on those that have long waiters.
11) Noting staff feedback that there are not clearly designated thresholds for accepting referrals for all conditions, further review of expectations for primary care consultations prior to referral for planned care is recommended, to assist with improved management of patient expectation and potentially reduce the number of referrals being accepted.
12) Finally, it is recommended that the potential to enhance co-production with patients from outpatient stage be considered to reduce the number of patients who are listed and subsequently opt not to be treated.

4. FINANCIAL IMPLICATIONS

There are no financial implications noted at this stage but as the action plan is developed there may be some requirement for investment.

In addition to this the Health Board has identified resources through its annual plan for 2019/20 to invest in additional capacity to stabilise waiting times and make services sustainable. Discussion are ongoing with Welsh Government regarding our plans address the backlog of long waiting patients in the context of the sustainability work already underway.

5. RECOMMENDATIONS

Members are asked to: -

- **NOTE** the content of the review report
- **NOTE** that an action plan will be developed to address the recommendations within the review

- **NOTE** that future Quality and Safety Committee meetings will receive updates on progress against the plan
- **NOTE** that the report will also be presented to audit Committee at its March 2019 meeting

Governance and Assurance							
Link to corporate objectives ***(please ✓)***	Promoting and enabling healthier communities	Delivering excellent patient outcomes, experience and access	Demonstrating value and sustainability	Securing a fully engaged skilled workforce	Embedding effective governance and partnerships		
		✓					
Link to Health and Care Standards ***(please ✓)***	Staying Healthy	Safe Care	Effective Care	Dignified Care	Timely Care	Individual Care	Staff and Resources
		✓			✓	✓	

Quality, Safety and Patient Experience

By implementing the recommendations of this report patients who are experiencing long waits for surgery will have enhanced experience and improved safety.

Reducing waiting times across the Health Board, as per its annual plan, will have benefits across all three aspects of quality, safety and experience.

Financial Implications

An assessment of any financial and/or workforce requirement will be made through the development of the action plan to address the recommendations within this report.

Legal Implications (including equality and diversity assessment)

Any matter of confirmed harm could result in a case against the Health Board.

Staffing Implications

None noted at this stage (see comments in financial implications above).

Long Term Implications (including the impact of the Well-being of Future Generations (Wales) Act 2015)

Access to safe, timely, appropriate care will provide long term benefits and will prevent the decoration of patients' health as a result of long waiting times.

Report History	This is the first issue of this report. RTT access times are routinely reported to the Executive Team and the
Appendices	**Appendix A** – Full report from NHS Wales Delivery Unit "Review of the Impact of Long Waits for Planned Care on patients"

Review of the Impact of Long Waits for Planned Care on Patients

ABERTAWE BRO MORGANNWG ULHB REPORT

November 2018

Review Lead:	Elizabeth Beadle, Performance Improvement Manager
Assistant Director Leads:	Philip Barry, Assistant Director – Scheduled Care
	Julie Parry, Assistant Director – Quality and Safety
Delivery Unit Director	Jeremy Griffith

EXECUTIVE SUMMARY

BACKGROUND

In response to concern about increasing numbers of patients waiting 52 or more weeks for planned care, for whom the impact was not widely understood, the NHS Wales Delivery Unit (DU) undertook a Wales-wide review of long waits for planned care. The review sought to assess the impact of long waits for patients in terms of potential harm and adverse outcomes and to seek assurance that organisations have robust processes in place to safeguard patients and to address the issues underlying extended waits for treatment.

This report sets out the review's specific findings in relation to Abertawe Bro Morgannwg University Health Board. The key messages from the review relate to the examination of waiting lists with patients waiting greater than 52 weeks at the end of September 2017, case notes review for a sample of these patients, patient feedback and discussions with Health Board staff. The feedback is representative of the findings relating to this cohort of patients.

KEY MESSAGES

Patient Impact

Generally, long waiting patients were not found to be at any higher risk of an emergency attendance at hospital and/or inpatient admission than patients waiting fewer than 52 weeks. However, case review highlighted that a small number of patients attended as an emergency and some received their treatment following emergency admission. Moreover, the review evidenced that that significant numbers of long-waiting patients are experiencing low-level harm with smaller numbers experiencing moderate (to severe) harm.

Impacts were found to be multifaceted; many patients reported constant or frequent adverse effects on their daily lives including pain, worsening symptoms, reduced physical function and emotional distress. Case review backed these findings but to a smaller extent, due to limited review points in the patient pathway. The limited information on patient-reported impact in case notes highlighted the need for improved (and more proactive patient contact) during long waits for treatment.

Areas of greatest concern

While some patients had positive outcomes from treatment despite their protracted wait, others had poor experiences. This was particularly evident for complex patients and those on multiple planned care pathways where the DU found scope to improve patient-focused coordination of activity for patient benefit and to reduce risk of adverse outcomes. Whilst small in number, the starkest examples were of patients who were treated only after an emergency admission, and of patients who died before receiving treatment.

Management of clinical risk

Processes to manage risk while patients wait are generally reactive relying on patient feedback or primary care expedite referrals, with a subsequent impact on primary care capacity and risk that some patients may not seek assistance when required. Significant gaps between service

contacts with patients exacerbate the potential for patients to experience avoidable harm; gaps between contacts greater than 12 months were commonplace. Based on these findings and the evidence of harm in the case review, it was not possible to be assured that robust systems are in place for managing clinical risk for patients who have long waits for planned care.

Resource utilisation

The DU observed instances of repeat investigations and of multiple cancellations of surgery with associated repeated cycles of pre-assessment, detracting from patients' experience and resulting in avoidable cost to the Health Board in terms of additional secondary care appointments. This also disadvantages other patients whose care is delayed due to this "rework".

Governance

Clear performance management and quality and safety structures were described and there was demonstrable awareness of some of the key areas of risk for planned care. Nonetheless, the DU found scope to improve connectivity between these processes to ensure that risk and safety considerations fully inform performance decisions and vice versa.

Concerns information provided to the DU highlighted that whilst the complaints data reflected a body of concern from patients about the length of waits for planned care, the low level of incident reporting did not align with the DU's findings in terms of adverse patient impact from long waits.

Improvement action

Health Board colleagues informed the DU of improvement that had been made and plans to further address specialities of concern to improve waiting times. However, staff described a range of factors affecting delivery of planned care and there remains a substantial cohort of patients waiting longer than 52 weeks for treatment and a significantly greater number of 36-week breaches. Consequently, strengthening the risk management processes to safeguard these patients while they await treatment is vital.

Notable practice

The Health Board has trialled an enhanced consent process with additional patient education with a view to improving patient understanding of risks and benefits of surgery. It is anticipated that this will increase the likelihood that patients who consent to surgery will not subsequently opt out. Lessons learned may potentially have wider applicability for other specialities.

RECOMMENDATIONS

The Delivery Unit's recommendations to Abertawe Bro Morgannwg University Health Board are listed below, in the order that they appear in this report. Please refer to the relevant pages of the report for the supporting evidence and conclusions. It is recommended that this report be presented to the Health Board's Executive Board's quality and patient safety committee for consideration of the findings and recommendations for action.

It is recommended that the Health Board:

1. Implements a proactive review of patients at clinically determined points during the pathway, and at 52-weeks as a minimum. Harm review literature from NHS England provides an evidence base for the value of undertaking such views to identify whether patients have experienced any harm/adverse impacts. The DU is proposing Wales-wide debate to construct and implement a proactive harm review process.
2. Implements a mortality review process for patients who die after a wait greater than 36 weeks for planned treatment, to seek assurance that the delayed treatment was not a contributory factor to avoidable harm.
3. Seeks to install a PAS system alert for patients with more than one RTT pathway and reviews processes to ensure that a discussion is held between the multi-disciplinary teams to manage interdependencies in the patient's care and to support the patient to prioritise treatment.
4. Reviews processes for primary and secondary care collaboration for complex patients on more than one pathway.
5. Reviews its communication and engagement processes for patients on RTT pathways, with a particular focus on ensuring that contacts and appointments with patients facilitate patients' feedback, and patients are made aware of how to contact the Health Board in the event of a change in their condition/symptoms. The national work on patient reported outcome measures and patient reported experience measures provides a framework for some planned care pathways; there is scope for the Health Board to expand its use of this framework.
6. Reviews how concerns data (including incidents and near misses) for long waits is recorded and used at quality & safety meetings and how widely this is disseminated and informs planning for improvement.
7. Reviews the use of local risk managements systems to ensure that incident and complaint data can be identified for the same episode of care.
8. Raises awareness amongst staff of the importance of reporting near misses and early identification of acts or omissions along the patient's pathway to facilitate learning to prevent similar situations from arising.
9. Reviews the use of concerns data to identify trends and share learning for a range of specialties across the Health Board.
10. Reviews the criteria for acceptance of referrals and listing for treatments with a high volume of ROTT, with a particular focus on those that have long waiters.
11. Noting staff feedback that there are not clearly designated thresholds for accepting referrals for all conditions, further review of expectations for primary care consultations prior to referral for planned care is recommended, to assist with improved management of patient expectation and potentially reduce the number of referrals being accepted.
12. Finally, it is recommended that the potential to enhance co-production with patients from outpatient stage be considered to reduce the number of patients who are listed and subsequently opt not to be treated.

INTRODUCTION

During 2017, the NHS Wales Delivery Unit (DU) highlighted concern that despite a reduction in the number of patients in Wales waiting in excess of 36 weeks on a referral to treatment (RTT) pathway the number of patients waiting over 52 weeks had been growing. Moreover, it was felt that the impact of these long waits was not well understood. Emerging reports from England have subsequently identified harm to patients arising from protracted waits for treatment.

Consequently, the DU work programme incorporated a plan to undertake a review with two key objectives. Firstly, to assess the impact of long waits for patients in terms of potential harm and adverse outcomes resulting from the extended delay. Secondly, to seek assurance that there are adequate clinical and operational risk management processes in place to safeguard patients and to address the issues underlying extended waits for treatment.

This report summarises the findings of the review for Abertawe Bro Morgannwg University Health Board (the Health Board) and is supplemented by a summary report setting out the themes identified across Wales and recommendations with wider applicability.

REVIEW METHODOLOGY

The review comprised three main phases: data analysis, site visits and patient feedback.

Data analysis

Data analysis comprised two main elements; examination of waiting lists for planned care alongside national emergency and deaths datasets and review of concerns data.

Waiting list analysis incorporated scrutiny of RTT waiting list data at two census points (September and December 2017) for specialities with waits over 52 weeks at the September census point. Specialities with small numbers of 52-week waits were excluded, taking into account both individual Health Board and all-Wales status. Review of the two snapshots enabled identification of changes in the composition of the list.

The data were examined with reference to emergency activity databases and the Office for National Statistics Deaths Dataset using pseudonymised patient data. This clarified the volumes of long waiting patients who had accessed unscheduled care via attendances at emergency departments and/or had emergency admissions at any Health Board site across Wales from 30th September 2016[1] to 31st December 2017. Further detail on the data analysis is available in appendix 1.

A sample of the long waiting patients was selected for review. This incorporated patient pathways within the following categories:

1. Pathways with patients who had died.
2. Pathways with patients identified as still waiting as at the end of December 2017.

[1] 30th September 2016 was used as a proxy for the patients' commencement on the RTT pathway to facilitate the review of the total cohort.

3. Pathways identified as being removed from the waiting list as at the end of December, either through treatment or removal other than treatment (ROTT).
4. Categories 1 to 3 were further stratified by patient pathways where an emergency department (ED) attendance or emergency admission could be identified from the national data and those with no record of an emergency activity.

Health Boards were also requested to submit data on numbers of concerns (complaints, incidents and claims) for the period January to December 2017, supplemented with qualitative analysis of themes observed by the Health Board and the impact of learning from concerns on service development.

Site visits: Meetings with Health Board teams

The DU review team met with Health Board colleagues with operational and executive remits for planned care and quality and safety. The discussions provided an understanding of the processes for managing planned care, the safeguards in place to ensure that patients are safe while they await care and to expedite treatment when necessary, and governance mechanisms for providing assurance to the executive team and board. Discussions with directorates were with the specialities with the largest volumes of 52-week breaches at the beginning of the review.

Site Visits: Case notes and patient administration system (PAS) review

The Health Board provided access to patient case notes via the Document Management System (DMS) for the sample identified from the data analysis and facilitated access to the PAS via designated Health Board colleagues. In 11 instances, there was limited information available on the DMS and the Health Board subsequently provided the full patient notes. This review focused on understanding each patient's planned care pathway and whether any emergency activity was recorded for this patient during the period of their wait for assessment and treatment.

In total, 92 cases were included in the analysis.

Sample population requested	Sample population available	Sample population where pathway could not be fully reviewed
92	92	0

Patient feedback

Health Boards issued questionnaires on behalf of the DU to a randomly selected sample of patients who had waited 52 weeks or more at the end of September 2017 to seek patient views on their experience of awaiting treatment. Returns were issued to and collated by the DU. A hundred questionnaires were issued to Abertawe Bro Morgannwg University Health Board patients. Thirty-two questionnaires were returned; amongst these were five patients who were resident out of the Health Board area but had been on a waiting list for planned care at the Health Board. Amongst the respondents, 34.5% reported that they had been treated, 62.5% indicated that they were still awaiting treatment and 3% did not confirm their current status.

ASSESSING IMPACT AND HARM

In order to provide a structured framework for identifying and classifying harm, the DU reviewed a number of national documents and undertook a wider review of literature relating to long waits for planned care elsewhere in the UK. Appendix 2 sets out the literature review summary and lists the references.

The literature review identified variations in the examples of what may constitute harm and how this should/could be graded. More recent documents that were designed specifically for assessing harm for RTT patients provide a positive supplement to documents intended to have general use as they supply pertinent examples for planned care. The threshold for harm varies between documents; this highlights the challenge presented by the need to make a subjective judgement on harm. Psychological harm was referenced almost universally but was not always supported by harm ratings, potentially due to the difficulty in making judgement of impact of waits for treatment on psychological wellbeing.

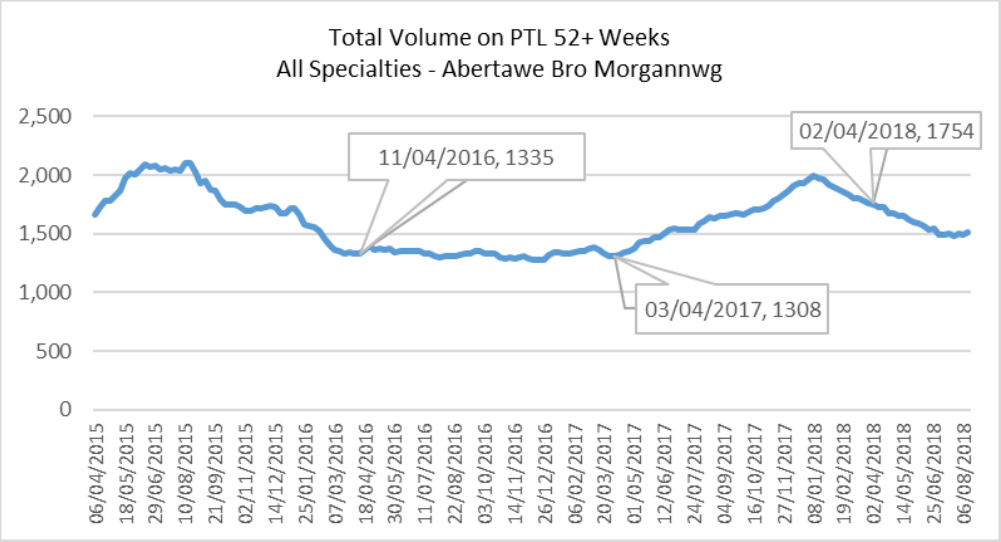
A fundamental finding from the literature review was that Health Boards need to consider multiple tools to achieve a more holistic understanding of harm. Using only a single tool risks limiting the judgement to clinical harm only and omitting the wider perspective of impact of waits on patients including their mental health.

When reviewing individual patients' cases, unless an instance of harm clearly fell into a specific grading, the review team considered the range of potential categorisations prior to finalising the findings set out in this report.

WAITING LIST PROFILE

For the past three financial years, significant numbers of patients have experienced waits of 52 weeks or more at Abertawe Bro Morgannwg University Health Board. Following a period of reduction in 2015 and fairly stable numbers during 2016, the volumes of long waits grew again during 2017 and peaked in January 2018. During 2018 volumes of long waits have reduced but have not yet re-attained the lower figures noted during 2016.

Figure One: Total volume of 52+ week waits (Source: Weekly PTL reports)



Long waits have been observed consistently in several specialities including Ear Nose and Throat, General Surgery, Oral Surgery and Trauma and Orthopaedics. However, there has been improvement in long waits for Ophthalmology, with long periods with no 52-week breaches during 2017 and numbers of patients waiting greater than 52-weeks being consistently lower than 15 during 2018. Conversely, Urology saw greater numbers of patients waiting over 52 weeks during 2017, although figures have subsequently improved during 2018.

During the waiting list review period, Orthopaedics consistently accounted for the majority of 52-week breaches. The next greatest volumes were concentrated in General Surgery and Oral Surgery with the remaining long waits were distributed among a number of specialities including. The specialities included in the scope of the review were Cardiology, ENT, General Surgery, Ophthalmology, Oral Surgery, Orthopaedics, and Urology; the remaining specialities were excluded, based on the analysis described in the methodology section.

FINDINGS

1. Patient reported impact

The patient questionnaire response highlighted that significant numbers of long-waiting patients are experiencing adverse impact that constitutes low-level harm, with a small cohort experiencing moderate harm. The reported experience of a small number could potentially be assessed as constituting significant harm.

1.1 Impact on daily life

81% of respondents to the DU's patient survey reported constant or frequent adverse effects on their daily lives, such as pain, reduced physical function, and emotional distress. The strength of feeling of patients was evident in the fact that all patients who reported adverse impact took the time to describe the effects in their response. 53% of respondents reported difficulty with mobility and/or undertaking activities of daily living.

"I cannot walk as well as I want and cannot walk for long periods (longer than 10 minutes) without constant pain whilst walking and for a long period of time afterwards."
Patient A, awaiting Orthopaedics treatment.

"Due to shortness of breath unable to walk any distance or complete daily living tasks without help and getting worse."
Patient B, who reported 18 months waiting for treatment on a Cardiac pathway.

1.2 Impact on social and economic activity

Several patients reported impact on family and social activities, and a small number (6 of 32) described adverse impact on their employment ranging from missing difficulty in undertaking their job to being unable to work or having to take less well-paid employment. Whilst the inability to work results from the condition rather than from an action by the service provider, the inability to provide the treatment will be the limiting factor for patients whose treatment is anticipated to relieve their symptoms and/or improve functioning.

1.3 Impact on mental health

19% of patients told us their mental health was affected by their long wait for treatment. The case review identified only one instance of a patient reporting any depression to the Health Board during their wait and two further patients for whom pre-existing depression was indicated. This gave rise to the concern that patients may be unlikely to disclose any adverse effects on their mental health unless asked, or alternatively, that mechanisms by which such discussions are being held with patients are not routinely recorded in the patients' notes. Consequently, it was not possible to provide assurance that the psychological wellbeing of patients was being robustly addressed.

"I suffered pain which made me depressed. I spent a lot of time in bed. Family life suffered. I can't face the pain and discomfort of going out much so it is isolating."
Patient C, awaiting Orthopaedic treatment.

1.4 Deteriorating health

37.5% of patients reported that their health/their condition had deteriorated while they were awaiting treatment. In the main, this deterioration referred to the condition for which the patient was awaiting treatment. However, some respondents noted impact on other aspects of health, such as weight loss. One respondent indicated that adjustments to their steroid medication in preparation for their orthopaedic procedure adversely affected other health conditions. Some of the harm review structures reviewed graded such deterioration as moderate harm.

2. Data analysis and case note review

2.1 Data review: Characteristics of and changes in waiting list composition

At the September census, there were 1548 long waiting patient pathways in the waiting list data[2]. Six specialities were represented, Cardiology, ENT, General Surgery, Oral Surgery, Orthopaedics and Urology.

The data review found no correlation between waits over 52 weeks and increased incidence of emergency attendances and/or admissions. However, the case review highlighted incidences of patients requiring unscheduled assessment/treatment related to the condition for which they were awaiting planned care. Of the 1548 cases, 564 pathways (36%) had evidence that patients attended and/or were admitted as an emergency between September 2016 and December 2017 compared with 42% of patients waiting fewer than 52 weeks (for the same specialities).

Between September 2017 and December 2017, 308 patients (20%) were treated and a further 146 (9%) removed from the waiting list. 1080 cases (70%) were still awaiting treatment at 31st December 2017. Fourteen long waiting patients had died. The specialities with patients who had died were Cardiology, General Surgery, Oral Surgery and Orthopaedics. There was evidence to indicate that one of the fourteen deceased patients had received treatment prior to their death.

2.2 Case note review

The DU undertook the case note review between 21st and 25th May 2018, 8 months after the September census.

Amongst the cohort for review, the majority (58%) had waited between 53 and 69 weeks as at September 2017. A further 31% of patients had waited between 70 and 99 weeks. Ten percent had waited more than 100 weeks, with the longest wait at 170 weeks, which was for General Surgery.

At the time of the review, 57% of patients in the sample had been treated, however, 23% of the cohort reviewed was still awaiting treatment. The remaining 20% comprised patients who

[2] N.B. This is broadly representative of the total profile of waits greater than 52 weeks for the Health Board, but the DU did not request waiting list data for specialities with low numbers of long waits. Hence, the figure differs from the total reported 52-week breach figure reported by the Health Board for September 2017.

were deceased (12%), six who had decided against treatment and two who had been removed from the waiting list by the Health Board.

Status at review	Number of patients	Percentage of review cohort
Treated	52	57%
Still waiting	21	23%
Other (removed)	2	2%
Patient decided against treatment	6	6%
Deceased	11	12%
Total	92	100%

Whilst the age of patients varied from under 10 years of age to over 90, the majority of patients were aged between 40 and 89. The numbers of long waiters in each decade (between 40s and 80s) were broadly similar. The proportion of these patients still waiting for treatment at the time of review varied. The greatest proportion still waiting was patients in their 20s, followed by those in their 40s and patients aged 60-69. There was only one patient in the cohort aged over 90. This patient was still awaiting treatment at the point of review.

2.3 Impact on patients

Case review evidenced that while some patients had eventual positive outcomes from treatment despite their protracted wait, other patients experienced adverse effects/outcomes.

In recognition that the review was limited to the patient notes supplied and the information held in the PAS, the DU applied a cautious assessment of harm. In practice, this meant that where an instance of harm could be assessed within two categories, the lowest was applied. The DU identified the majority of patients who experienced harm in the low category in the main due to prolongation of symptoms. However, the ability to assess harm was limited by the apparent lack of explicit framework for recording patients' baseline and any subsequent change in clinical presentation and symptoms. This appeared to be addressed exclusively in clinical correspondence. Some of the further examples given below may be assessed as moderate harm:

- The patient requiring additional investigations (2 patients) with potential associated cost (for travel and time away from employment) and possibly anxiety;
- Impact on other aspects of the patient's health (e.g. weight loss);

The case study below highlights the wider impact of not receiving timely treatment.

Patient Case Study X

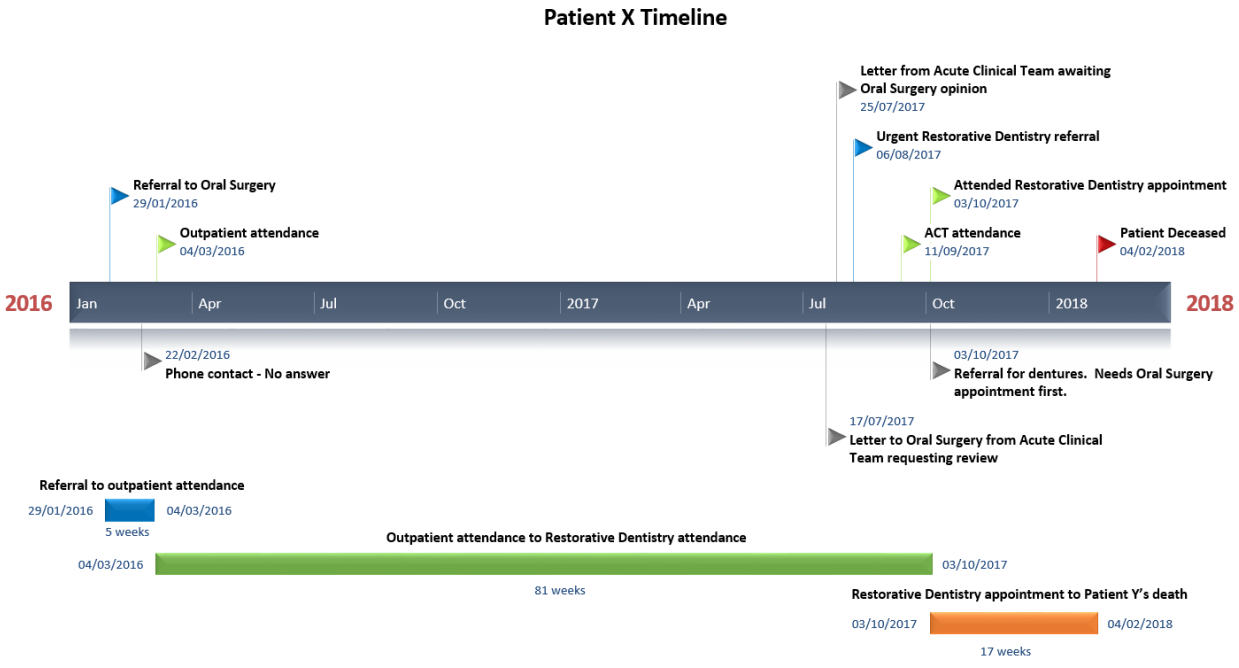
Patient X was originally referred to Oral Surgery in 2014 and this pathway was reinstated in January 2016 and reclassified as urgent. Following a first outpatient appointment in March 2016 the only record of activity was an adjustment in November 2016.

Patient X was seen by the Acute Clinical Response Team (ACT) 14 months after the outpatient appointment. The ACT team contacted Oral Surgery, noting that the patient had been due to be seen by the Oral Surgery team but had been ill, and requesting assessment, highlighting concern that Patient X was losing weight due to difficulty chewing.

Patient X was referred to Restorative Dentistry for assessment for dentures in August 2017 and was seen in October 2017. The outcome was that Patient X wished to proceed with dentures but required root extraction from Oral Surgery to proceed first.

Patient X died in early 2018. There was no record of treatment prior to Patient X's death.

The review team noted that in October 2017 there was a record of this patient also having swallow difficulties. Therefore, it appeared that later in this patient's pathway there were other factors affecting the patient's weight. However, the statement from the ACT team in August 2018 was clear that the patient's dental status was considered to be adversely affecting the patient's weight at this time.



Incidences of moderate harm were also noted by the review team:

- Patients experiencing worsening symptoms and/or increasing pain (9 patients);
- Increase in need for medication or treatment.

Five percent of the cases sampled for review attended and/or required admission as an emergency, due to their condition. Two of these patients received their planned treatment following an emergency admission; one case is detailed below as case study Y. 6.5% of the case review cohort had their priority status increased during their pathway due to their symptoms or pain and there was evidence of progressive symptoms and/or increased pain recorded in patient notes for three further patients. In total, 15% of the cases reviewed were affected.

Patient Case Study Y

Patient Y was referred to Orthopaedics in August 2016 and attended a first outpatient appointment in December 2016. The outcome was that Patient Y was listed for total hip replacement. Patient Y was described as having bone on bone arthritis with severe pain and was taking morphine to manage pain at this time.

Patient Y underwent pre-assessment in May 2017 and had a further appointment arranged for 27th September 2017. Patient Y's record indicates that they should not be booked for four weeks due to chest infection. However, on 4th October 2017 Patient Y was admitted as an emergency and the total hip replacement was undertaken (60 weeks after the original referral). By November 2017, at post surgery review Patient Y was able to mobilise with a stick and was described as having a good range of pain-free movement.

2.4 Areas of greatest concern

Of greatest concern to the DU was the evidence of the impact of long waits for patients with co-morbidities, particularly those on multiple RTT pathways and the missed opportunity to treat patients whose health declined during their protracted wait.

The DU found no evidence that the ten deceased patients in the review sample had been treated prior to their death. Two of these patients had a record of could not attend (CNA) and one did not attend (DNA) noted on their PAS record, however two were inpatients at the time of non-attendance. All three incidences of non-attendance were late in the patients' pathway and therefore were not a mitigating factor for the length of wait.

The review team noted that changes in patients' health were not always evident. In one instance, a patient was assessed as fit for surgery on their RTT pathway and referred for urgent suspected cancer assessment three weeks later. This patient died 6 weeks after the USC referral.

It was not possible for the DU to determine whether there was any link between the long wait and any of the patients' deaths. However, it is concerning that four of the ten patients who

died had been on Cardiology pathways undergoing assessment for or awaiting transcatheter aortic valve implantation (TAVI).
The DU noted opportunity to improve co-ordination for patients with co-morbidities on more than one planned care pathway and those on tertiary pathways where advice or information from other specialities is required and/or guidance in prioritising treatments. An example is a request for patient notes from another tertiary centre for a TAVI patient that was progress chased almost three months after the initial request; this patient died before receiving treatment.

2.5 Typical pathways and patient experience

The DU observed that long-waiting patients are experiencing delay for initial outpatient assessment and/or long waits after listing for treatment. Gaps between appointments/reviews are frequently considerable, with little or no apparent communication during these periods of delay. This was also reflected in the patient feedback. 31% of survey respondents reported that they had not been contacted during their wait to ascertain whether treatment was still required. This highlights that current, reactive systems result in poor patient experience for some patients and do not adequately manage risk for patients whose condition may deteriorate while waiting.

The review found instances of repeat investigations following a period of delay and patterns of multiple cancellations of treatment/surgery, which extended patients' overall wait. One patient's treatment was cancelled 3 times. Whilst unavailability of beds or staff are often the cause of cancellations, this occurrence is detrimental to patient experience and results in avoidable cost to the Health Board in terms of wasted/repeated appointments in secondary care (e.g. where pre-assessment is required to be repeated). The impact of repeated investigations and cancellations on patients was not explicit in the cases reviewed; however, the psychological impact of cancellations may be substantial.

2.6 Management of clinical risk

Rather than proactive failsafe mechanisms to manage risk, the DU observed and was informed of reactive systems requiring patients to contact the Health Board if their condition changes while they are awaiting treatment. These include patient feedback direct to the secondary care team, or via primary care expedite referrals, with a subsequent impact on primary care capacity and risk that some patients may not seek assistance when required, or until actual harm has occurred. Significant gaps between appointments or contact from services exacerbate the potential for patients to experience avoidable harm while they wait. Consequently, under the current system, the Health Board cannot be assured that patients are not coming to harm while they await care.

65% of patients in the case review sample had a gap greater than 6 months between appointments. Of these, more than half had gaps of 12 months or more. The review team noted adjustments in 35 patient's cases which contributed to the patients' wait; some patients had more than one adjustment applied. Nonetheless the frequency of significant gaps between appointments/contacts is of concern.

Longest time between appointments/direct contact with patient	Number of patients
2-5 months	9
6-11 months	28
12 months or more	32
Unclear/unknown	23
Total	**92**

Interviews with Health Board staff revealed differing perspectives on the risk of harm to patients arising from long waits for planned care. For example, the perception of risk of harm to patients awaiting an orthopaedic procedure ranged from low risk to potential risk of death for frail patients for whom immobility presents increased risk of acquiring infection.

2.7 Recommendations

It is recommended that the Health Board:

1. Implements a proactive review of patients at clinically determined points during the pathway, and at 52-weeks as a minimum. Harm review literature from NHS England provides an evidence base for the value of undertaking such reviews to identify whether patients have experienced any harm/adverse impacts. The DU is proposing Wales-wide debate to construct and implement a proactive harm review process.
2. Implements a mortality review process for patients who die after a wait greater than 36 weeks for planned treatment, to seek assurance that the delayed treatment was not a contributory factor to avoidable harm.
3. Seeks to install a PAS system alert for patients with more than one RTT pathway and reviews processes to ensure that a discussion is held between the multi-disciplinary teams to manage interdependencies in the patient's care and to support the patient to prioritise treatment.
4. Reviews processes for primary and secondary care collaboration for complex patients on more than one pathway.
5. Reviews its communications processes for patients on RTT pathways, with a particular focus on ensuring that contacts and appointments with patients facilitate patients' feedback, and patients are made aware of how to contact the Health Board in the event of a change in their condition/symptoms. The national work on patient reported outcome measures and patient reported experience measures provides a framework for some planned care pathways; there is scope for the Health Board to expand its use of this framework.

3. Governance

Health Board colleagues described the intent to reduce long waits, with a focus on reducing the number of specialities with 52-week breaches initially. This is supported by the reducing trend for 52-week waiters since early 2018.

3.1 Structures and Processes

Clear performance management and quality and safety structures were described to the DU, with processes for escalation of risks, issues and concerns from directorates through Health Board Delivery Units to the Executive team and Board. However, there is scope to improve connectivity between these processes.

Speciality and Health Board Delivery Unit processes

- Speciality teams described the lead roles for the performance management and quality and safety management structures and processes. Given that performance and safety meetings are separate entities with different membership, there is a risk that decision-making may not be supported by a full understanding of risk and learning from concerns.
- Teams reflected that waiting times were amongst the top themes for complaints from patients and it was clear that this was a real concern.
- Rightly, the process for managing complaints included clinical review to assess whether the patient's urgency had changed, with appropriate action taken where required. However, the DU observed that it was distressing for the teams dealing with complaints from patients given that they were sometimes unable to achieve reprioritisation for patients experiencing quite significant impact on their daily lives.
- In some discussions, it emerged that the significant volume of long waiting patients engendered a feeling amongst staff that treating the backlog was an insurmountable problem.
- Feedback suggested that where risk of adverse impact was identified in relation to social and economic factors, it was less likely that the risks would be highlighted and cases reassessed to consider whether they required expediting.
- All units had undertaken a review of long waits in 2017. Feedback on this review varied. Whilst many staff reported that the longest waits can be for complex patients who must be treated on a major acute site, conversely, some services/units reported that there had been no expedites as a consequence of the review and that the impact of waits was on patients' quality of life rather than clinical risk. One service reported that some patients' urgency status was downgraded with no complaint from the patients. The DU was informed that consideration had been given to implementing proactive review of patients waiting over 52 weeks but such a system was not in place at the time of the review.

Corporate processes

- It was evident that corporate level priorities for improvement reflected learning from previous serious incidents, and performance risks. However, escalation processes tend to focus on the areas assessed as highest risk and the Health Board may be missing opportunities for significant improvement identified through near misses and no-harm incidents.
- Equally, some Health Board colleagues reflected that a focus on areas with significant numbers of long waits risks missing greater risk in other specialities (or sub-specialities).

3.2 Concerns information

The Health Board provided the DU with data on concerns specifically relating to waits/delay for planned care for the 2017 calendar year.

Concern	Number
Complaints	1680
Incidents	9
Near misses	2
Claims	2 (1 new, 1 settled)

Complaints data highlights a body of concern from patients about the length of waits for planned care with 1680 making a complaint to the Health Board in 2017. It is unclear whether this includes both formal and informal concerns. The speciality with the greatest volume of complaints was Orthopaedics, reflecting the high number of long waiting patients.

The reported incidents comprised 2 negligible, 3 minor and 4 moderate across 7 service areas. Orthopaedics was the only service with multiple incidents (3).

Both claims were for General Surgery; it was unclear whether the new and settled claim were the same or whether these were two separate claims.

It was difficult to make reliable comparisons between Health Boards' concerns submissions for a number of reasons including population size, varying numbers of long-waiting patients and different service structures. However, it is notable that Abertawe Bro Morgannwg University Health Board reported the highest number of complaints but the second lowest number of incidents.

Given the low number of incidents and near misses alongside a high volume of complaints, it appears that overall concerns data understates both the occurrence of issues and the impact of long waits on patients.

3.3 Recommendations

It is recommended that the Health Board

6. Reviews how concerns data (including incidents and near misses) for long waits is recorded and used at quality & safety meetings and how widely this is disseminated and informs planning for improvement;
7. Reviews the use of local risk management systems to ensure that incident and complaint data can be identified for the same episode of care;
8. Raises awareness amongst staff of the importance of reporting near misses;
9. Reviews the use of concerns data to identify trends and share learning for a range of specialties across the Health Board.

4. Addressing waiting times

4.1 Factors affecting service capacity

Discussion with Health Board colleagues elicited a range of factors considered to adversely affect capacity to treat elective patients. These ranged from the physical environment (e.g. access to theatres) and staffing deficits resulting from turnover or difficulty to recruit to posts in some sub-speciality areas, plus the impact of unscheduled care activity on scheduled care.

Whilst the reason for delay in accessing outpatient appointments was not discernible from case note review, some of the long waits after listing were clearly attributable to cancellations for treatment/surgery due to constraints noted by staff, such as lack of beds.

Processes for triage/prioritisation, and listing for surgery varied between specialities. Speciality teams indicated that for many conditions there were not agreed thresholds for accepting referrals or listing for procedures. Triage/grading of referrals is undertaken by individual consultants in the main, but with multi-disciplinary teams for some cohorts or patients/conditions. Peer review did not appear to be commonplace where triage of referral was undertaken by an individual staff member. Addressing variation in practice to reduce the number of patients unnecessarily accessing secondary care pathways will reduce the volume of wasted appointments and should consequently improve access times for patients who require services.

4.2 Improvement plans

Units and speciality teams each described the areas causing them greatest concern and also articulated the actions that had secured existing improvements in waiting times. These ranged from the commissioning of outsourced activity, to investment in new and/or additional permanent roles (for example the development of nurse-led treatment for Ophthalmology), alongside shorter-term locum posts.

Some future plans were described, however concern was raised that there had been a reliance on short-term solutions rather than a focus on a longer term strategy for planned care improvement.

4.3 Notable practice

The Health Board has trialled an enhanced consent process using a web-based educational tool as a supplement to the existing risk-benefit discussions between clinicians and patients which in partnership with the Royal College of Surgeons of Edinburgh (Consent Plus). This is thought to enhance the likelihood that patients who consent to surgery will proceed with accessing their treatment, as they have better understood the risks and benefits.

4.4 Recommendations

It is recommended that the Health Board

10. Reviews the criteria for acceptance of referrals and listing for treatment for treatments with a high volume of ROTT, with a particular focus on those that have long waiters.

11. Noting staff feedback that there are not clearly designated thresholds for accepting referrals for all conditions, further review of expectations for primary care consultations prior to referral for planned care is recommended, to assist with improved management of patient expectation and potentially reduce the number of referrals being accepted.
12. Finally, it is recommended that the potential to enhance co-production with patients from outpatient stage be considered to reduce the number of patients who are listed and subsequently opt not to be treated.

CONCLUSIONS

The Health Board is aware of factors affecting waits for planned care and is seeking to take steps to improve services, but there remains considerable work to achieve sustainable delivery of timely planned care across all specialities.

Therefore, it is fundamental that the Health Board prioritises review of its practices to safeguard patients while they await planned care. The current system does not proactively review patients regularly on their pathway and the review evidenced that some patients are coming to harm while they wait and many are experiencing adverse impacts daily.

Current systems and processes do not support the Health Board to understand the impact of prolonged waits for treatment on patients and address this accordingly; this can be achieved through proactive patient review, supported by improved communication with patients throughout their pathway and enhanced learning from concerns.

NEXT STEPS

A national report highlighting the key findings and themes from the review will be presented to the Welsh Government. Given a number of recurring issues and recommendations across Wales, the DU will recommend that consideration be given to facilitating Wales-wide debate to shape key structures and processes to assess and mitigate risk of harm to patients experiencing long waits for planned care and ultimately, to eradicate long waits.

At the request of Health Boards, the DU will meet with Health Board colleagues to discuss the findings of the review further, in support of local implementation of the report's recommendations.

APPENDICES

Appendix 1 – Data review

Summary of analysis of long waiters' emergency attendances and admissions

Number of PATHWAYS	Died *(as recorded in ONS Deaths Dataset as at 16/7/2018)*	Still Waiting - on WL as at e/o Dec 2017, same spec, any length wait. No record of death before 16 July 2018	Treated* (Non emergency admission method Activity in APC, same HB, same spec). No record of death before 16 July 2018	Not on List (ROTT or Other) (Total minus other columns). No record of death before 16 July 2018	**Total**
Attended ED or Emergency admission in Wales, under any specialty during period **20160901 to 20171231***1	11	384	108	61	**564**
No evidence of ED attendance or emergency admissions during this time period*1	3	696	200	85	**984**
Total	**14**	**1,080**	**308**	**146**	**1,548**

Summary of review of long waiters in conjunction with ONS Deaths Dataset

Died details (# of PATHWAYS)	
Treated* (Non emergency admission method Activity found in APC, same HB, same spec) in review period **20170930 to 20171231**	1
No evidence of treatment under above criteria	13
	14

Appendix 2 – Literature Review

Assessing and Grading Harm to Patients Awaiting Planned Care

Harm assessment structures generally comprise five levels from no harm to severe harm and finally death. The documents reviewed vary in the degree to which they incorporate impacts on the patient beyond clinical impact/harm; however, existing Welsh guidance (Putting Things Right, 2013) makes provision for impact on patients' lives in both the low and moderate harm categories.

The types of harm in these categories include loss of working time, requirement for additional treatment, and the cancellation of appointments in addition to clinical or process issues that result in avoidable injury or impairment of health that require intervention.
More recently, NHS England has been considering how to identify and classify harm for patients who have been awaiting planned treatment on Referral to Treatment (RTT) pathways. The types of harm identified include prolongation and worsening of symptoms. In some documents, the psychological impact of prolonged waits on the patient is more fully recognised and integrated.

Assessing Psychological Harm

Putting Things Right makes provision for the recognition of patients' dissatisfaction in the no harm category, but does not include any examples of assessment of psychological impact of a patient concern related to planned care in the harm rating. There are examples supplied in Appendix Q of payments made to patients, which include recognition of psychological consequences of an incident/event.

Seven Steps to Patient Safety stresses the importance of grading incidents according to harm and that this should include psychological "injuries such as shock, anxiety, depression…" (Page 98).
The difficulty in making a judgement on psychological harm is referenced in NHS England's Clinical Harm Review Handbook, noting that patients' baseline is not assessed at the point of referral.

Harm Ratings

Grade/Harm Rating	Putting Things Right Guidance (2013)	NHS England External Clinical Harm Review Handbook (2016) (Definitions for RTT pathway)	Seven Steps to Patient Safety (2004)	Barking, Havering and Redbridge University Hospitals Clinical Harm Review Programme Document
1/ No harm	a) Concerns which normally involve issues that can be easily / speedily addressed; b) Potential to cause harm but impact resulted in no harm having arisen; c) Outpatient appointment delayed, but no consequences in terms of health; d) Difficulty in car parking; e) Patient fall – no harm or time of work; f) Concerns which have impacted on a positive patient experience.		No harm: • Impact prevented–Any patient safety incident that had the potential to cause harm but was prevented, resulting in no harm to people receiving NHS-funded care. • Impact not prevented–Any patient safety incident that ran to completion but no harm occurred to people receiving NHS funded care.	In the clinician's opinion, the patient has suffered inconvenience only.
2/Low	a) Concerns regarding care and treatment which span a number of different aspects/specialities; b) Increase in length of stay by 1 - 3 days; c) Patient fall - requiring treatment; d) Requiring time off work - 3 days; e) Concern involves a single failure to meet internal standards but with minor implications for patient safety; f) Return for minor treatment, e.g. local anaesthetic or extra investigations.	Prolongation of symptoms	Any patient safety incident that required extra observation or minor treatment and caused minimal harm, to one or more persons receiving NHS-funded care. Minor treatment is defined as first aid, additional therapy, or additional medication. It does not include any extra stay in hospital or any	In the clinician's opinion, the patient has suffered inconvenience e.g. prolonged discomfort not leading to need for significantly stronger analgesia or causing psychological harm. In the clinician's opinion the patient has suffered inconvenience or symptoms that, whilst not

Grade/Harm Rating	Putting Things Right Guidance (2013)	NHS England External Clinical Harm Review Handbook (2016) (Definitions for RTT pathway)	Seven Steps to Patient Safety (2004)	Barking, Havering and Redbridge University Hospitals Clinical Harm Review Programme Document
			extra time as an outpatient, or continued treatment over and above the treatment already planned. Nor does it include a return to surgery or re-admission.	sufficient to warrant a 'moderate' conclusion have sufficient impact to warrant a letter of apology and explanation; Example 1 – a child has multiple episodes of tonsillitis requiring antibiotics and resulting in school absences; Example 2 – an adult is awaiting a total knee replacement and during the extended wait suffered continuing pain (although not requiring stronger analgesia) and interruption to activities of daily living because of poor mobility
3/ Moderate	a) Clinical / process issues that have resulted in avoidable, semi permanent injury or impairment of health or damage that require intervention; b) Additional interventions required or treatment /	Increase in symptoms. Increase in medication or treatment.	Any patient safety incident that resulted in a moderate increase in treatment and which caused significant but not permanent harm, to one or more persons	In the clinician's opinion, the patient has suffered moderate physical or psychological harm. For example, if there was a delay treating a locally

Grade/Harm Rating	Putting Things Right Guidance (2013)	NHS England External Clinical Harm Review Handbook (2016) (Definitions for RTT pathway)	Seven Steps to Patient Safety (2004)	Barking, Havering and Redbridge University Hospitals Clinical Harm Review Programme Document
	appointments needed to be cancelled; c) Readmission or return to surgery, e.g. general anaesthetic; d) Necessity for transfer to another centre for treatment / care; e) Increase in length of stay by 4 -15 days; f) RIDDOR Reportable Incident; g) Requiring time off work 4 -14 days; h) Concerns that outline more than one failure to meet internal standards; i) Moderate patient safety implications; j) Concerns that involve more than one organisation;		receiving NHS-funded care. Moderate increase in treatment is defined as a return to surgery, an unplanned re-admission, a prolonged episode of care, extra time in hospital or as an outpatient, cancelling of treatment, or transfer to another area such as intensive care as a result of the incident.	invasive basal cell carcinoma such that a larger cosmetic procedure was required this would be moderate harm unless it causes significant psychological harm in which case it should be classified as severe harm.
4 / Severe	a) Clinical process issues that have resulted in avoidable, permanent harm or impairment of health or damage leading to incapacity or disability; b) Additional interventions required or treatment needed to be cancelled; c) Unexpected readmission or unplanned return to surgery; d) Increase in length of stay by >15 days;	Irreversible progression of disease. Death on the waiting list from index condition.	Any patient safety incident that appears to have resulted in permanent harm to one or more persons receiving NHS-funded care. Permanent harm directly related to the incident and not related to the natural course of the patient's illness or underlying condition is defined as	

Grade/Harm Rating	Putting Things Right Guidance (2013)	NHS England External Clinical Harm Review Handbook (2016) (Definitions for RTT pathway)	Seven Steps to Patient Safety (2004)	Barking, Havering and Redbridge University Hospitals Clinical Harm Review Programme Document
	e) Necessity for transfer to another centre for treatment / care; f) Requiring time off work >14 days; g) A concern, outlining non-compliance with national standards with significant risk to patient safety; h) RIDDOR Reportable Incident;		permanent lessening of bodily functions, sensory, motor, physiologic or intellectual, including removal of the wrong limb or organ, or brain damage.	
5/ Death	a) Concern leading to unexpected death, multiple harm or irreversible health effects; b) Concern outlining gross failure to meet national standards; c) Normally clinical/process issues that have resulted in avoidable, irrecoverable injury or impairment of health, having a lifelong adverse effect on lifestyle, quality of life, physical and mental well-being; d) Clinical or process issues that have resulted in avoidable loss of life; e) RIDDOR Reportable Incident;		Any patient safety incident that directly resulted in the death of one or more persons receiving NHS funded care. The death must relate to the incident rather than to the natural course of the patient's illness or underlying condition.	

Overview of focus on planned care and psychological impact/harm

	Putting Things Right Guidance (2013)	NHS England External Clinical Harm Review Handbook (2016) (Definitions for RTT pathway)	Seven Steps to Patient Safety (2004)	Barking, Havering and Redbridge University Hospitals Clinical Harm Review Programme Document
Is harm for RTT patients explicitly featured?	Includes examples of harm that may arise on RTT pathways (e.g. delayed outpatient appointment) despite being a document intended to cover all aspects of patient care.	Yes. Designed to support clinical harm review with suggested definitions of harm for RTT pathways listed.		Yes. Designed to support RTT clinical harm review.
Is psychological impact on patients addressed?	The harm rating references patient dissatisfaction (no harm only. Appendix Q includes examples of payment to patients for incidents where there has been a psychological impact.	References psychological harm but does not including in harm definitions. Makes reference to the difficulty in assessing psychological harm due to a lack of baseline at referral to RTT pathway.	Notes that "Psychological injuries such as shock, anxiety, depression, uncertainty about recovery, fear of future treatment and disruption to work and family life are just some of the possible effects following a patient safety incident." (Page 98)	This is considered in the example provided for the moderate grading and references severe psychological harm.

Documents reviewed

Barking, Havering and Redbridge University Hospitals, (Dr M. Smith, Associate Medical Director), How to Set up and Run a Clinical Harm Review Programme for RTT and Long Waiting Patients

Harm2 Tool from Mayor S, Baines E, Vincent C, Lankshear A, Edwards A, Aylward M, et al. Measuring harm and informing quality improvement in the Welsh NHS: the longitudinal Welsh national adverse events study. Health Serv Deliv Res 2017;5(9)

NHS England, External Clinical Harm Review Handbook (2016)

National Patient Safety, Agency Seven Steps to Patient Safety – The Full Reference Guide (2004)

Putting Things Right Guidance on dealing with concerns about the NHS from 1 April 2011 (Version 3 November 2013)

Appendix 3 – Acknowledgements

The DU would like to extend grateful thanks to colleagues at Abertawe Bro Morgannwg University Health Board for their full support and participation in undertaking this review. The review team would like to note particular thanks to all colleagues who were interviewed during phase two of the review and to colleagues in Information, Medical Records, Patient Experience and RTT teams for supplying information prior to site visits, access to patient notes and PAS records, and facilitating the patient survey.

Appendix 4 – Terms of Reference

Terms of Reference for a Review of the Impact of Long Waits for Planned Care on Patients

1. Terms of Reference

This document specifies the agreement between the Delivery Unit (DU) and Cardiff and Vale University Health Board (HB) in undertaking a review of the impact of long waits for planned care on patients.

2. Background

The Delivery Unit has identified a concern that despite a reduction in the number of patients in Wales waiting in excess of 36 weeks on a referral to treatment (RTT) pathway the number of patients waiting over 52 weeks has grown.

Across Wales there are currently 22,898 patients on a referral to treatment (RTT) pathway who have waited in excess of 36 weeks[3]. Of these, there are 5363 patients who have waited over 52 weeks for treatment. 1267 of the (52-week) patients' cases are classified as urgent. The majority of urgent waits over 52 weeks are for Orthopaedics (860), General Surgery (173) and Urology (101) and the distribution of patients is in the main in three Health Board areas[4].

3. Rationale/Aims

The rationale for the proposed review is to assess the impact of long waits for patients in terms of potential harm and adverse outcomes resulting from the extended delay.

The output of this work will be a report summarising the findings of the review and recommendations for action to ensure that there are adequate clinical risk management processes in place to safeguard patients and to address the issues underlying extended waits for treatment.

The key outputs incorporated in the report will include:

- Identification of the volumes of long-waiting patients being conveyed to/attending accident and emergency departments;

[3] Data as at week commencing 28/08/2017. Source: Weekly PTL.
[4] Urgent patients waiting over 52 weeks on an RTT pathway at 03/04/2017: Abertawe Bro Morgannwg University Health Board – 390, Betsi Cadwaladr University Health Board – 443, and Hywel Dda University Health Board – 301.

- Identification of the volumes of long-waiting patients admitted as emergency admissions and the resultant impact on beds;
- Identification of the numbers of patients who are not discharged to their usual place of residence following admission;
- Identification of the themes and trends from concerns (incidents, complaints and claims) relating to long-waiting patients ;
- Assessment of the processes by which patients are selected and prioritised for treatment and the clinical risk management processes applied to ensure the safety of long-waiting patients;
- Assessment of the Health Boards' ownership and response to any issues arising from long waiting patients.

4. Review Arrangements

The review will be a joint undertaking of the Delivery Unit's Scheduled Care and Quality and Safety teams reporting to Mr Philip Barry, Assistant Director – Scheduled Care and Mrs Julie Parry, Assistant Director – Quality and Patient Safety. The lead will be Elizabeth Beadle, Performance Improvement Manager.

The Health Board lead will be ……..

5. The Approach

To attain the required level of understanding of the issues being considered the Delivery Unit will utilise a four-stage process.

The review will focus on patients who have waited longer than 52 weeks for commencement of definitive treatment.

5.1 Phase One – Data Review

The first stage of the work will consist of a data review.

I. Data extracts of patients awaiting planned care (RTT) at two points in time will be prepared. These will be assessed and categorised into populations to determine:
    - The number of patients whose treatment has commenced;
    - The number of patients who are still waiting;
    - Patients who have been removed from the waiting list for any other reason.
    - Whether any patients have died in the time between the two dates.

II. Data sets comprising emergency attendances, admissions and discharges will be requested for the 12-month period corresponding to the patients' wait on an RTT pathway. These will be reviewed to determine:
    - The number of Emergency Department (ED) attendances for the patients in the cohort within the twelve-month period during which they have been awaiting treatment;
    - The number of emergency admissions for these patients resulting from ED attendances and the category of admission;

- Discharge destination (to identify whether patients returned to their usual place of residence);
- Whether there are any discernible patterns relating to the emergency attendances/admissions and the priority categorisation for cases (priority/routine).

Statistically significant cohorts of patients will be selected from the sample population and Health Boards will be contacted and informed of the patient identifiers for these patients in order that patient records can be collated for review in phase 2. Health Boards will also be requested to extract details of concerns (incidents, complaints and claims) raised in relation to the duration of the wait for planned care during the time period being considered in the review.

5.2 Phase Two – Site Visits

1. Notes Review

The DU team will review patient notes to undertake detailed analysis of the reasons underlying the ED attendances, emergency admissions and discharge destination to identify whether there is evidence that the patients' long wait for planned care was a contributory factor and if there is evidence that any harm has occurred.

The notes review will also seek to establish how the learning from analysis of incidents resulting in harm is used to inform action to improve clinical risk management processes.

2. Meetings with Health Board Teams

The DU will meet with key individuals involved in the management of patients on RTT pathways. The meetings will cover the processes for;

- Assessing the relative clinical priority of patients;
- Selecting patients for treatment;
- Risk management arrangements for assuring the safety of patients while they await treatment (both clinical and corporate management of risk);
- Obtaining and using patient feedback to inform their clinical risk management processes;
- Investigation and analysis of concerns and implementation of actions identified for improvement.
- Service constraints impacting on ability to assess and treat patients.

5.3 Phase Three – Review of Patient Experience

The final phase of the review will focus on the patients' perspectives on long waiting times to identify whether/ how their wait for treatment has affected them. Health Boards will be requested to contact patients to ascertain whether they would be willing to provide feedback on their experience whilst awaiting treatment. Patients who are willing to participate will be requested to complete a questionnaire/ attend a focus group session.

5.4 Phase Four - Health Board Feedback

Following completion of phases one to three and in advance of issuing a final report summarising the findings of the review, feedback will be provided to each Health Board to assure that the organisation has an opportunity to understand the findings, and to provide further information if appropriate.

6. Process and Timescales of Review (*N.B. Timescales subsequently changed due to data availability.)

Phase/Activity	Date
1. Data Review: • Test phase (national data supplied by NWIS) • Full data analysis (data to be supplied by Health Boards)	September 2017 to November 2017
2. Site visits 2.1 DU to issue notification of visits, request for patient notes and support for patient survey. 2.2 Visits	 November 2017 December 2017 – January 2018
3. Patient experience review	January 2018
Analysis and report completion	January - February 2018
4. Feedback to Health Boards	February 2018

7. Outputs

The DU will produce a report which summarises the findings of the review, highlights areas of both concern and good practice. The report will make recommendations for improvement based on evidence and good practice.

8. Escalation

Identification of significant risk:

If during the review the DU identifies significant risk to staff or patient care, the DU will discuss the specific risks with the Lead Manager designated by the individual HB. It is the responsibility of the Lead Manager to confirm the actions to be taken by the HB to address the identified risk.

Escalation to the Executive Team:

If the DU remains concerned about the level of action taken, this will be escalated to the Executive Lead for the HB and the Welsh Government Lead.

Escalation to an appropriate External Agency

If the DU feels that the HB has not fully addressed the identified significant risk, this will result in escalation to the appropriate external agency.

The DU will be working closely with both Welsh Government and the UHBs and making recommendations for the purpose of further improving and developing the services. On signing this document, both the DU and UHB are agreeing to conduct the review under the above terms of reference.

----------	----------
UHB Executive Lead	Director, DU
Date: ----------	Date: ----------