

Gliocova: variation of care and outcome in brain tumour patients across England

Kerlann Le Calvez¹, Radvile Mauricaite¹, Lillie Pakzad-Shahabi², Matt Williams³

¹Imperial College Healthcare NHS Trust, ²John Fulcher Neuro-oncology Laboratory, Imperial College London, ³Computational Oncology Laboratory, Institute of Global Health Innovation

Presenting Author: Kerlann Le Calvez

Background: Primary brain tumours are the leading cause of cancer death in the under-40's and have the highest average number of years of life lost. Even with multi-modal maximal treatment (surgery, radiotherapy, and chemotherapy), the prognosis is poor and varies considerably between different disease (median overall survival is 15 months for grade IV glioblastoma; 5 years for grade III astrocytoma; 15 years for grade III oligodendroglioma; 7 – 20 years for grade II tumours). Apart from the gliomas, there is a range of rarer primary CNS tumours, such as ependymoma and medulloblastoma that are under-researched and with limited outcomes known due to the low incidence in the population.

Public Health England (PHE) hold linked national data on all major cancer treatments (surgery, radiotherapy, chemotherapy) for patients in England. The Gliocova project is an attempt to understand the patterns, and systematic variation in those patterns, in the diagnosis, treatment, outcomes and costs of adult patients with malignant glioma in England.

Method: The Gliocova project uses a comprehensive linked national dataset including data on incidence, surgery, chemotherapy, radiotherapy, hospital admissions and death, provided by PHE. We requested data on all adult patients with primary Central Nervous System (CNS) tumours diagnosed in England between 2013 and 2018, with a focus on primary malignant (ICD10-codes C70x-C72x) and benign brain tumours (D32x - Benign neoplasm of meninges, D33x - Benign neoplasm of brain and other parts of central nervous system, D352 - Benign neoplasm of pituitary gland, D353 - Benign neoplasm of craniopharyngeal duct, D354 - Benign neoplasm of pineal gland).

Results: Between 2013 and 2018, 51775 patients were diagnosed with a primary brain tumour (26239 malignant; 25623 benign). The most common types of brain tumours were glioblastoma (15294 pts) meningioma (14846 pts) and schwannoma (4463 pts). The median age was 64 years old and was similar in the male and female cohorts. Patients with a GBM had a median survival of 209 days (~ 7 months) and there was no difference in survival between males and females.

Implications: Although brain tumours are rare, they have a disproportionate impact on cancer survival. National cancer datasets allow us to understand the epidemiology and outcomes even for rare tumours. The Gliocova project offers us an opportunity to study both patterns of care, and variations in care and outcome at a national scale.

Changes in diagnosis, medication and survival in English heart failure patient cohorts ten years apart

Alex Bottle, Roger Newson, Benedict Hayhoe
Imperial College London

Presenting Author: Alex Bottle

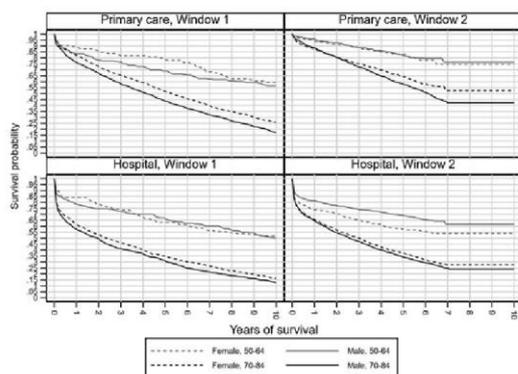
Background: Heart failure (HF) is a complex condition affecting more than 26 million people worldwide. In the UK most individuals with HF are managed in primary care by general practitioners (GPs). However, HF is not always a straightforward diagnosis to make in this setting and diagnostic uncertainty may contribute to ambiguity in treatment selection. Previous work has shown variation in HF prescribing between European countries, low compliance with NICE guidelines for HF diagnosis and initial management in England, and modest improvements in short-term survival. We extend this to compare processes and medium-term mortality in two cohorts ten years apart to see what has changed.

Method: Two HF cohorts were derived from the Clinical Practice Research Datalink for participating English GP practices with linkage to hospital admission and death registry data, with patients diagnosed in 2001-2 (window 1) and 2011-2 (window 2). Cohorts were described and compared on factors including demographics, blood pressure, total cholesterol, comorbidities, electronic Frailty Index (eFI), NICE guideline compliance (echocardiogram, referral to cardiologist), prescribing and mortality with up to 15 years of follow-up (window 1).

Results: There were 5,966 patients in 156 practices in 2001-2 and 12,827 patients in 331 practices in 2011-2. Window 2 patients were older than those in window 1, with lower blood pressure (mean systolic BP fell from 145 to 136 mmHg, $p < 0.001$) and cholesterol (5.2 to 4.6 mmol/l, $p < 0.001$) but greater comorbidity and frailty, had more non-HF hospital admissions, were more likely to see the GP and practice nurse, and were more likely to live alone. Just over one in three had had a home visit in both cohorts, and around one in six had had an out-of-hours appointment before diagnosis.

The use of beta-blockers rose from 24.3% to 39.1% and renin-angiotensin system acting (RAS) medications rose from 31.8% to 54.3%, but there was no change in thiazide diuretics and little for loop diuretics. For the 9963 patients with HF symptoms recorded by their GP before diagnosis, within 6 months of presentation with such symptom(s) in primary care, serum proBNP testing was low in window 2 (8.1%; the test was not available in window 1), echocardiogram use rose from 8.3% to 19.3%, and specialist referral rose from 7.2% to 24.6%.

Among all patients combined, five-year survival was 40.0% in window 1 (40.2% in window 2); ten-year survival in window 1 was 20.8% and 15-year survival 1.1%. Improvement was seen only in those diagnosed in primary care (five-year survival 46.0% in window 1 and 57.4% in window 2, compared with 33.9% and 32.6% for hospital-diagnosed patients). Gender differences narrowed only for primary care diagnosed patients. The Figure shows age-gender survival by window and diagnosis setting: survival improved for all ages and genders only for those diagnosed in primary care.



Graphs by Heart failure diagnosis setting and Heart failure diagnosis window

Implications: Long-term survival after a diagnosis of heart failure showed some improvement over the ten years if diagnosis was made in primary care but was unchanged if following a hospital admission. The ten years saw populations ageing and the existence of greater frailty but also showed falls in blood pressure and cholesterol and rises in compliance with NICE guidelines, (though it remains low). These findings highlight the potential impact on health outcomes where individuals with HF are appropriately diagnosed and managed in primary care; further research is needed to understand how best to support primary care clinicians in identifying and managing individuals with HF in order further to improve outcomes.

Primary Care Streaming in Emergency Departments- Contexts and Mechanisms Associated with Perceived Effectiveness Outcomes: A Realist Evaluation

Michelle Edwards¹, Alison Cooper¹, Freya Davies¹, Thomas Hughes², Andrew Carson Stevens¹, Pippa Anderson³, Helen Snooks³, Alison Porter³, Bridie Evans³, Niro Siriwardena⁴, Matthew Cooke⁵, Jeremy Dale⁵, Peter Hibbert⁶, Adrian Edwards¹

¹Cardiff University, ²John Radcliffe Hospital, Oxford, ³Swansea University, ⁴University of Lincoln, ⁵University of Warwick, ⁶Macquarie University

Presenting Author: Michelle Edwards

Background: Recent policy has encouraged emergency departments (EDs) to deploy nurses to stream patients from the ED front door to GPs working in a separate GP service operating within or alongside an ED. We aimed to describe mechanisms relating to effectiveness of streaming in different primary care service models identified in EDs. We explored perceptions of whether patients were perceived to be appropriately streamed to emergency care, primary care, other hospital services or community primary care services; and effects on *patient flow* (including effects on waiting times and length of stay in the ED); and *safe streaming outcomes*.

Methods: A realist evaluation methodology was used to explore perceived streaming effectiveness. We visited 13 EDs (purposely selected across England & Wales; 8 streamed primary care patients to a primary care clinician) and carried out observations of triage/streaming and patient flow and interviews with key members of staff (consultants, GPs, nurses). Field notes and audio-recorded interviews were transcribed verbatim and were analysed by creating context, mechanism and outcome configurations to refine and develop theories relating to streaming effectiveness. We integrated a middle range psychological theory (cognitive continuum theory) with our findings to recommend a focus for training nurses in streaming and service improvements.

Results: Higher band, more experienced emergency department nurses and nurse practitioners were perceived to be more knowledgeable and skilled in their role and have more confidence in their clinical judgement, they integrated their experience and intuitive knowledge with local guidance when assessing patients and make better decisions about which streaming pathway patients are allocated to and improving patient flow. They were also perceived to make better decisions about discharging and redirecting patients to community primary care services and were more confident in communicating their decision to patients. Less experienced nurses were perceived to be less effective in streaming primary care patients because they sometimes lacked knowledge of which types of patients can be seen by GPs were not aware of their scope of practice in terms of access to investigations or capacity to make referrals. They also may order unnecessary investigations, meaning that patients have to wait longer and spend more time in the emergency department. Where there was no clear guidance established in relation to which patients GPs could see the effectiveness of streaming on patient flow was limited because GPs could be selective in which patients they saw. Without

clear protocols, guidance or training available less experienced nurses were at risk of missing red flags during an initial assessment and inappropriately streamed patients needing emergency care to a primary care service, causing concern for patient safety. In terms of management, clinical directors and senior nurses recognised the importance of having the most experienced nurses streaming at the front door. In some EDs managers at other times monitored and supervised streaming to help improve flow and temporarily suspended primary care streaming to avoid overwhelming the primary care service.

Implications: Our findings highlight key mechanisms relating to the effectiveness of primary care streaming in different models of service. We recommend a collaborative approach to service development, guidance and training (including input from ED clinicians and primary care clinicians) and a range of training strategies that are suitable for less experienced junior nurses and more experienced senior nurses and nurse practitioners. Further research is needed to understand more about the development of streaming protocols and guidance, to understand the extent to which streaming criteria match with the needs of both the emergency care and primary care services, and the experience and the skill-sets of nurses carrying out streaming and the clinicians within the primary care team.

Variations In Care of Hospitalised Patients with Congestive Heart Failure and Diabetes Across 11 Countries

Hannah Knight
The Health Foundation

Presenting Author: Hannah Knight

Background: The proportion of the population with multi-morbidity is growing within countries, making care provision more complex. Many systems are facing the challenge of optimizing service delivery for multi-morbid patients, and the need to integrate services to do so. The presentation will look at the variations in utilisation and spending of elderly patients are hospitalized with congestive heart failure and have a comorbidity of diabetes. Pooling together quantitative data and qualitative information from selected countries, this study aims to outline the differences in care trajectories across countries, which can help better inform what optimal systems for this population may look like.

Method and Data: Using a commonly agreed upon clinical vignette representing a patient aged 65-90 years with congestive heart failure and diabetes, a common methodology was applied to identify and follow patients in linked administrative datasets across 11 high income countries. Where possible, the analysis is extended to explore the entire pathway of care, spanning primary care services, specialty services, acute hospital care, and post-acute care. Further, spending and utilisation data from the year following the index hospitalisation for congestive heart failure and diabetes will be compared with the data from the prior year.

Results: In total 77,328 patients were included in the study. The median age was 79 years. All 11 countries could reliably examine patient-level linked care in inpatient and outpatient hospital settings and 7 could further link to primary care, home health and post-acute rehabilitative care. The presentation will examine between-country variation in health service utilisation and spending, as well as outcomes including 30-day mortality and readmission.

Implications: This work is an important contribution to other cross country comparisons that highlights differences in service delivery for multi-morbid patients, particularly those with congestive heart failure and diabetes.

Exploring Patient Safety Outcomes for People with Learning Disabilities in Acute Hospital Settings: A Scoping Review

Gemma Louch¹, Abigail Albutt¹, Joanna Harlow-Trigg², Sally Moore³, Kate Smyth⁴, Lauren Ramsey¹, Jane O'Hara²
¹NIHR Yorkshire and Humber Patient Safety Translational Research Centre, ²University of Leeds, ³Bradford Institute for Health Research, ⁴Lancashire Teaching Hospitals NHS Foundation Trust

Presenting Author: Gemma Louch

Background: It is clear from previous research that certain demographic factors are associated with increased likelihood of poorer health, and variation in the use of and access to healthcare services. One population that may experience greater vulnerabilities in terms of health and healthcare inequalities are people with learning disabilities. These vulnerabilities might arise as a result of barriers to accessing services and challenges associated with service organisation and delivery. The 2019 Learning Disabilities Mortality Review (LeDeR) report highlighted that people with learning disabilities died from an avoidable medical cause of death twice as frequently as people in the general population, and that the greatest difference between people with learning disabilities and the general population was in relation to medical causes of death which are treatable with access to timely and effective healthcare. There is clear evidence that people with learning disabilities may be more at risk in terms of patient safety in hospital as well as known challenges around recognising and reporting patient safety incidents in this population. Therefore, the need to bring together what is known about the safety of people with learning disabilities receiving healthcare, is clear. This scoping review aimed to produce a narrative synthesis of published academic and grey literature focussing on patient safety outcomes for people with learning disabilities in an acute hospital setting.

Methods: Scoping review with a narrative synthesis. We searched four research databases from January 2000 to November 2019, in addition to hand searching and backwards searching using terms relating to our eligibility criteria – patient safety and adverse events, learning disability, and hospital setting. Following stakeholder input, we searched grey literature databases and specific websites of known organisations until March 2020. Potentially relevant articles and grey literature materials were screened against the eligibility criteria. Findings were extracted and collated in data charting forms.

Results: 41 academic articles and 34 grey literature materials were included, and we organised the findings around six concepts: 1) Adverse events, patient safety and quality of care; 2) Role of family and carers; 3) Understanding needs in hospital; 4) Maternal and infant outcomes; 5) Post-operative outcomes; and 6) Supporting initiatives, recommendations and good practice examples. People with learning disabilities appear to experience poorer patient safety outcomes in hospital. The involvement of family and carers, and understanding and effectively meeting the needs of people with learning disabilities may play a protective role. Promising interventions and examples of good practice exist, however many of these have not been implemented consistently and warrant further robust evaluation.

Implications: Our review demonstrates the piecemeal and wide-ranging nature of the extant evidence, in terms of specific learning disabilities and outcomes of interest, and with a range of methodologies used. Therefore, we propose that research is needed to establish the burden of harm for people with learning disabilities as a result of patient safety incidents and poor quality of care, in hospital settings. This goes beyond learning from deaths – we need to understand what happens with care for people with learning disabilities more generally. Second, research needs to understand the mechanisms through which these effects might be seen. It is this approach that holds significant promise from the point of view of service improvement and redesign, as well as training and curriculum development. Put simply, we cannot change what we do not yet fully understand. Finally, attention must be given again to the existing recommendations from the range of reports already published. There is already a wealth of learning about the problems that exist for people with learning disabilities and their families; what is needed now is policy level action.

An Evaluation of Service User Experience, Clinical Outcomes and Service Use Associated with Urgent Care Services That Utilise Telephone Based Digital Triage: A Systematic Review

Vanashree Sexton, Jeremy Dale, Carol Bryce, Helen Atherton
University of Warwick

Presenting Author: Vanashree Sexton

Background: Telephone based digital triage is widely used by services that provide urgent care. This involves a call handler or clinician using a digital triage tool to generate algorithm based care advice, based on a patient's symptoms. Advice typically takes the form of signposting within defined levels of urgency to specific services or self-care advice. Despite wide adoption, there is limited evaluation of its impact on service user experience, service use and clinical outcomes; no previous systematic reviews have focussed on services that utilise digital triage, and its impact on these outcome areas within urgent care. This review aimed to address this need, particularly now that telephone based digital triage is well established in healthcare delivery.

Method: Studies assessing the impact of telephone based digital triage on service user experience, health care service use and clinical outcomes were identified through searches conducted in Medline, Embase, CINAHL, Web of Science, and Scopus. Search terms using words relating to digital triage and urgent care settings (excluding in-hours general practice) were used. The review included all original study types including qualitative, quantitative and mixed methods studies; studies published in the last 20 years and studies published in English. Quality assessment of studies was conducted using the Mixed Methods Appraisal Tool (MMAT); a narrative synthesis approach was used to analyse and summarise findings. This review is registered on PROSPERO (2020 CRD42020178500).

Results: Thirty three studies were included, most were conducted in the UK (n=17) and were of quantitative design (n=25). Frequent presenting symptoms included: abdominal problems, respiratory problems and pain. Calls made by women and calls about younger age groups made up high proportions of calls. Digital triage service use declined in patients with increasing age; however urgency of advice increased with age. Two studies reported that women were more likely to receive lower urgency advice as compared to men.

Eight studies reported on service use (primary care, ED use, ambulance use, and emergency admissions) following digital triage implementations. Most reported a reduction or no change in service use; one exception was a study that reported an increase in ED use, in comparison to service use prior to implementation.

Six studies reported varying patient adherence to triage advice, through evaluation of patients' subsequent ED attendance. Two studies highlighted potential safety concerns relating to under-triage.

Overall, service users reported good satisfaction. Three studies highlighted that callers felt they needed to be assertive in order to receive appropriate care. One study raised safety concerns, where users reported not receiving appropriate triage advice for their symptoms which later turned out to be serious.

Implications: This review highlights important areas for further research which will contribute to the improvement of digital triage tools and service delivery.

Most studies that investigated service use following digital triage were conducted at 'service level', following digital triage implementation. Further analysis of large patient level datasets will help to gain a better understanding of patterns within sub groups, including gender differences in advice urgency, who does and does not adhere to advice, and to evaluate safety concerns relating to under triage.

Future research using mixed methods approaches will be vital to better understand care needs of patients, and in identifying areas where digital triage does and does not work well. Research undertaken in the time period of the Covid-19 pandemic will also be important in understanding changes in care needs and service use.

