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- Electronic Healthcare Record - Eliminating a Disease - Plain Language Summaries using AI

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Guest Editorial

The Impact of Patient Advocacy on Care: A Regional Framework for the Assessment and Referral of Patients with Facial Palsy

Colin G Leonard

Facial palsy can occur at any stage of life and arises from a diverse range of pathological processes. The intricate interplay of facial musculature, together with the additional sensory and autonomic functions of the facial nerve—taste, lacrimation, and salivation—means that facial palsy presents with an extensive spectrum of signs and symptoms^{1,2}. While one patient may experience a mild reduction in facial function, another may suffer a complete loss of movement and form. Beyond the physical manifestations, facial palsy carries profound psychological and social implications for many patients^{2,3}.

Given this heterogeneity of cause and impact, the management of facial palsy requires input from a wide range of medical

and allied health professionals. Underlying aetiologies may necessitate the expertise of physicians, neurosurgeons, and otolaryngologists, while plastic surgeons contribute through medical, injectable, and surgical interventions aimed at restoring function and aesthetics. Ophthalmologists play a vital role in managing complications arising from impaired eyelid closure and corneal protection.

In many tertiary and quaternary centres, patients benefit from multidisciplinary assessment and treatment clinics. However, in Northern Ireland such structures have historically been lacking, leading to challenges in timely diagnosis and coordinated care. Over a decade ago, patients established a social media support group for individuals affected by

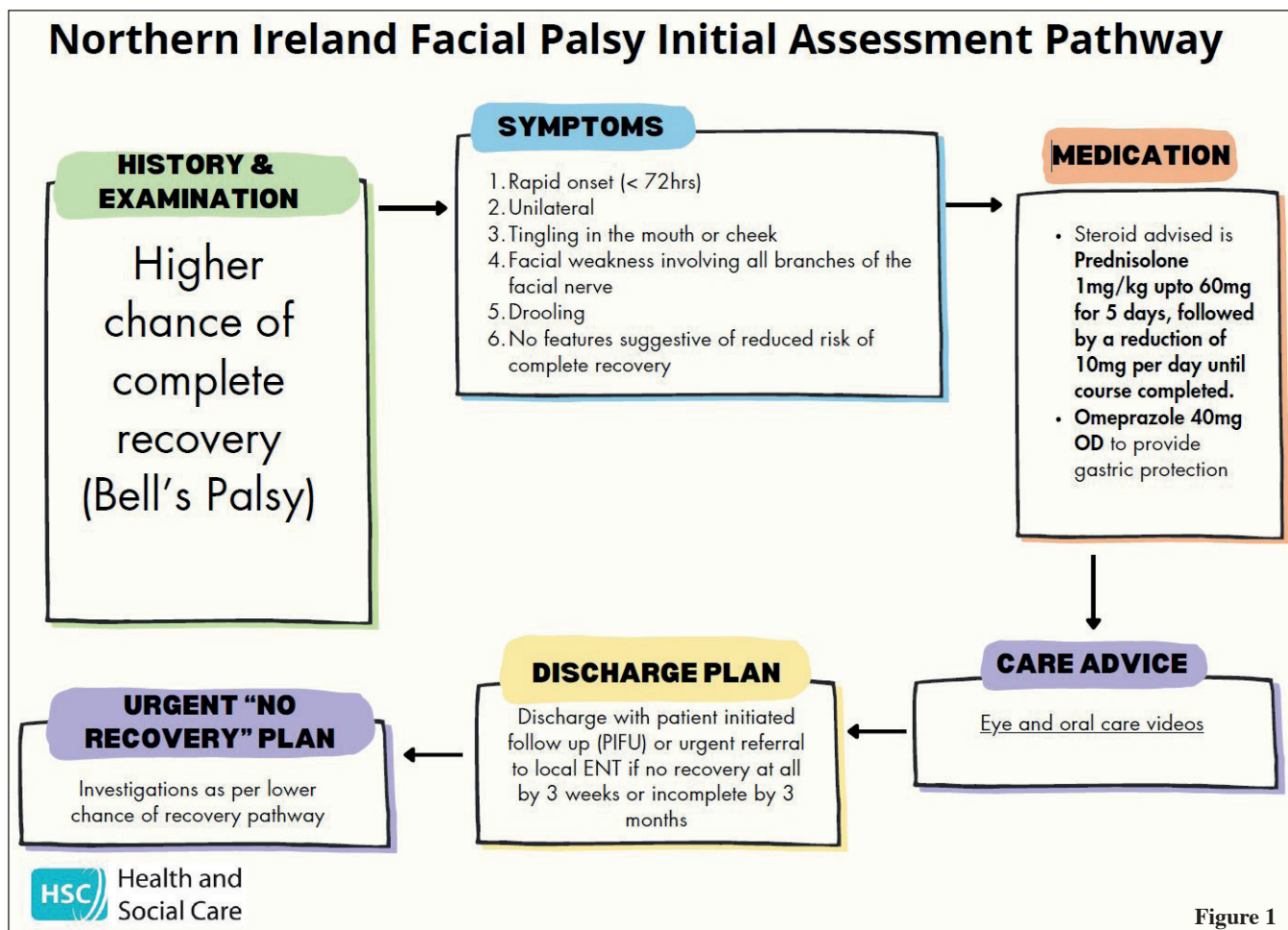


Figure 1

facial palsy—an initiative that has since grown to more than 300 members. Early stakeholder meetings before the COVID-19 pandemic ultimately led to the establishment of the Northern Ireland Facial Palsy Regional Planning Group and subsequently the Northern Ireland Facial Palsy Steering Group. These collaborative bodies unite patients, clinicians, policymakers, and representatives from the Strategic Planning and Performance Group (SPPG) to improve access to and quality of facial palsy care across the region.

Recognising the financial pressures on the health service, early efforts focused on optimising existing care within the framework of SPPG and Department of Health priorities. This approach emphasised delivering assessment and, where possible, treatment locally, while standardising care regionally. Key achievements of this initiative have been the development an NI Direct page for patients (<https://www.nidirect.gov.uk/conditions/facial-palsy>) and an evidence-based regional assessment pathway for adults and children presenting to primary care or emergency services with facial palsy.

The adult pathway was designed after reviewing local service structures, relevant evidence—including the NICE Clinical Knowledge Summary (CKS) for Bell's Palsy—and

with input from Facial Palsy UK. Several critical decisions shaped its development. Firstly, in contrast to the CKS the pathway encompasses *all* causes of facial palsy rather than focusing solely on idiopathic (Bell's) palsy, thereby reducing diagnostic errors and inappropriate labelling. Secondly, it stratifies patients into three groups:

1. Those likely to make a full recovery (idiopathic/Bell's palsy) with minimal need for specialist intervention.
2. Those with a reduced likelihood of full recovery, requiring moderate specialist input (management of primary causation, therapy to aid recovery, or surgical intervention for aesthetics, reanimation or reinnervation).
3. Those exhibiting concerning features necessitating urgent escalation to specialist care.

This stratification aims to ensure that the right patient is directed to the right service at the right time.

Patients with a high likelihood of complete recovery typically present with a rapid onset (<72 hours) unilateral lower motor neurone palsy, often preceded by perioral tingling, with involvement of all facial branches and no concerning features (Figure 1). Most begin to recover within two to three

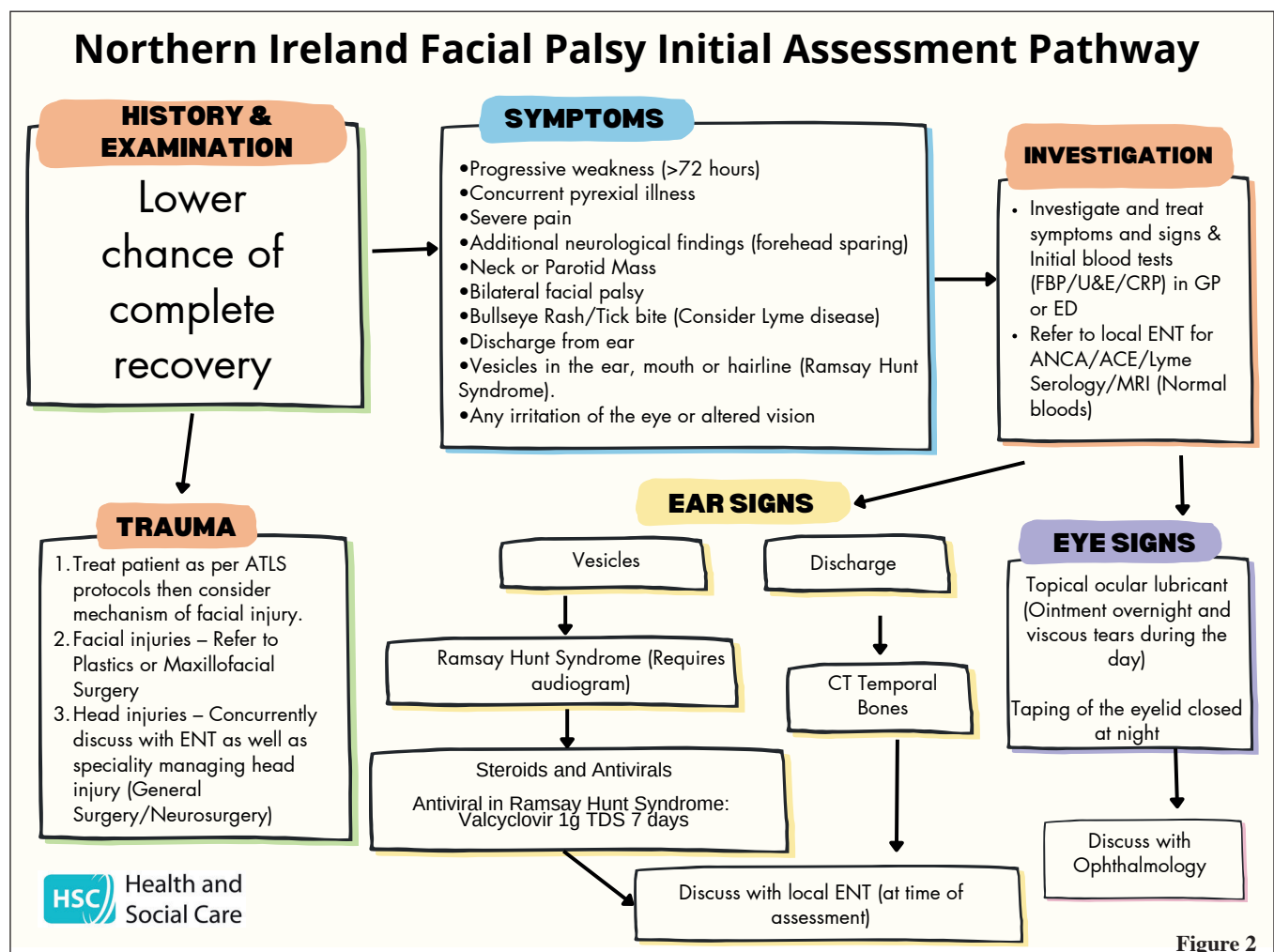
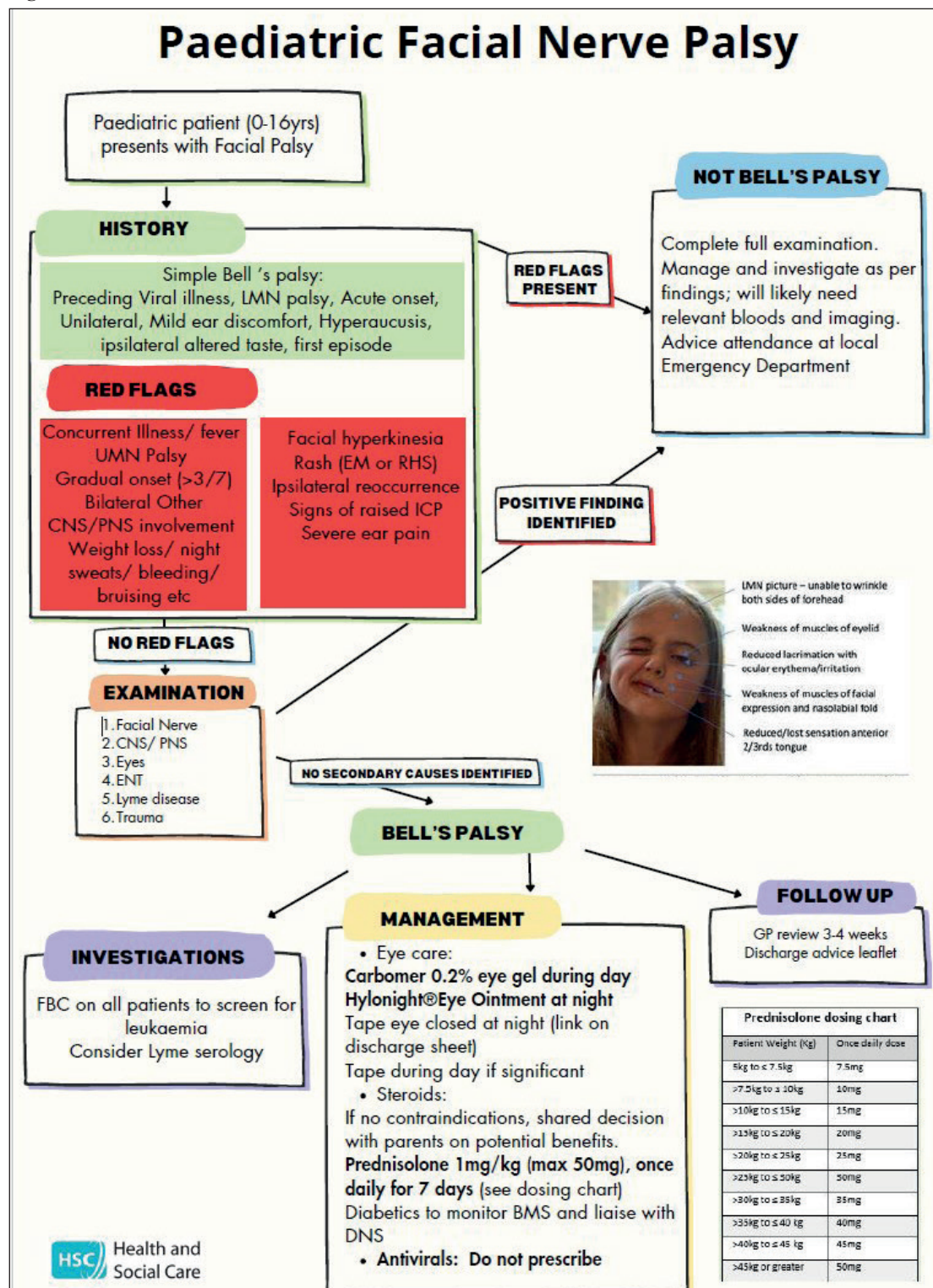


Figure 2

Figure 3



weeks, with approximately 90% achieving full recovery by six months for incomplete palsy and 70% for complete palsy⁵. Early treatment with prednisolone enhances recovery rates^{6,7}. Supportive care—such as eye protection and oral hygiene—remains vital, and patients may be signposted to Facial Palsy UK video resources for practical guidance.

Patients presenting with concerning features—including progressive weakness, pyrexia, pain, upper motor neurone involvement, neck or parotid masses, bilateral palsy, bullseye rash or tick exposure (Lyme disease), otorrhoea, vesicular

eruptions (Ramsay Hunt syndrome), or associated vertigo or hearing loss—require prompt investigation. The nature of these investigations will depend on presentation and clinical setting, as summarised in the second pathway flow chart (Figure 2).

In cases of trauma, management should follow Advanced Trauma Life Support (ATLS) principles, with subsequent referral to the appropriate specialty—Plastic Surgery for soft tissue injuries, Maxillofacial Surgery for bony injuries, or ENT in cases involving temporal bone fractures.

Patients who develop complications also require timely referral. Those with visual changes or irritation of the eye should be referred to Ophthalmology, while those showing no recovery at three weeks or incomplete recovery by three months should be referred to Plastic Surgery for further evaluation. Given the profound psychosocial impact of facial palsy, clinicians should also remain alert to signs of psychological distress and refer appropriately for psychological support.

The paediatric pathway is also structured to provide evidence-based care at point of service contact for those patients for whom this is suitable, whilst identifying those patients who need further input from specialist services (Figure 3).

Beyond pathway development, the Steering Group continues to address service provision challenges. Notably, to date there are currently no funded facial therapy services in Northern Ireland—despite evidence of their benefit for patients at risk of incomplete recovery and those undergoing reconstructive interventions⁸. This shortcoming was identified as a key challenge due to the high proportion of patients who would benefit and the need for therapy as an adjunct to surgical care. Ongoing advocacy and evidence-based lobbying have now secured funding; business and job plans are in development

It is hoped, that with development of the service, integrating the various stakeholder specialities into a multidisciplinary clinic will occur in time. In the interim, a positive outcome of the planning and steering groups has been much closer communication between and within specialities, with specialists utilising their skill sets to provide care to patients within their own services. Patients are already benefiting from earlier intervention and reduced risk of missing opportunities for care.

A further challenge is that the number of patients requiring the most complex surgical procedures will be relatively low in Northern Ireland, due to population size. It is with that in mind that the Plastic surgery department have forged connections with multiple world-class centres. These connections are being developed with the intention of supporting a future multidisciplinary team and in reach. It is hoped that this approach will ultimately improve the quality of care for all patients and provide local care for those complex patients who otherwise would have had to undertake significant travel.

Acknowledgements

I would like to acknowledge, firstly all the patients who have advocated for greater services to manage facial palsy. Their bravery in doing so, often in circumstances made challenging because of their symptoms is remarkable. Secondly, to all who have contributed to the Planning and Steering Groups, particularly those who have been working to improve care in this area for many years prior to my appointment in 2022. Their work both clinically and in the organisation of care across their specialities has been integral to the progress achieved to date.

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Clinical Paper

Evaluating the Implementation of a New Electronic Healthcare System in a Single Trust in Northern Ireland

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ABSTRACT

Introduction: This study assesses the implementation of the introduction of an electronic healthcare record (EHCR) into the South Eastern Trust (SET) in Northern Ireland.

Aims: To address the effect of the introduction of EHCR on clinical efficiency, initial implications for patient care and staff wellbeing, and to provide guidance from lessons learnt for future implementation.

Method: Doctors employed and medical students on placement within the SET were asked to complete an electronic Likert survey during the system's initial three months of implementation.

Results: There were 151 responses across 25 specialties. Overall, 81% did not experience an improvement in working efficiency. 50% of respondents anticipated that inpatient efficiency would improve with time, while 19% did not. In the outpatient clinic environment, only 25% believe that efficiency will be improved with time and adaptation. Regarding administration, 45% believe that following introduction, administrative tasks placed on doctors are disproportionate to their clinical value for patient care. 67% stated that there was less time for medical education and training.

Conclusions: Despite an initial overall negative response towards EHCR participants have a positive attitude towards its potential to improve patient care. Concerns relating to system usability and administrative burden imposed by Epic on senior staff remain apparent throughout the study. 'A perfect system would have doctors freed up to do what we are trained to do'. Usability issues were identified as contributory to this dissatisfaction. Inadequate training was identified as a factor which made adaptation more challenging. This in particular is a consideration for those trusts yet to implement Epic.

Keywords: Change, Adaptation, Training, Usability, EHCR

Introduction

The National Health Service (NHS) has begun a process of digitising the electronic healthcare records (EHCRs) in the United Kingdom. EHCRs are deemed to improve efficiency, effectiveness, and safety, ultimately enhancing patient care¹.

In November 2023, the South Eastern Trust (SET) in Northern Ireland implemented an EHCR (Epic). This marked the initial transition to a fully digitised paperless health care service in Northern Ireland. Prior to this launch, Northern Ireland used a combination of paper notes and EHCRs.

Epic is widely used in North America. Now its software is being introduced within hospitals across Europe and Asia². Its introduction within Northern Ireland is set to be "revolutionary" providing complete healthcare information from a single platform which can be accessible at any time and from anywhere³, enabling staff to simultaneously order investigations, record information and complete administrative tasks. Epic also facilitates communication between doctors, nurses, allied healthcare professionals and patients⁴. The introduction of the Epic system in Northern Ireland is being facilitated by the Encompass project.

This study documents the initial experience of SET medical staff during the initial three months of the introduction of Epic. This research aims to determine the effects of Epic regarding clinical efficiency, quality of patient care, student teaching and the impact on staff wellbeing.

Methodology

Medical staff working for the South Eastern Trust were asked to voluntarily complete a Likert-type survey via Microsoft forms. The questionnaire was accessed through a QR code distributed on a business card. Participants ranged from consultants to medical students on placement within trust. Questions were designed to allow exploration of three main themes: clinical efficiency; effect on patient care; and effect on staff professional and personal wellbeing (*Appendix 1 – Table 5*).

Participants were asked to rank their level of agreement with a stem statement by selecting one of: strongly agree, agree,

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neutral, disagree and strongly disagree. Participants were given the context in which they should answer the questions - they were asked to compare the new EHCR (Epic) with the clinical record system(s) they had been using prior to launch. Responses were converted into a measurable five-point numerical scale to create a positivity score. This was the case in all questions except statements 1-4 where the scale was reversed (negative phrasing of statements). Statements 5-26 were positively phrased. The higher the score, the more positive the response towards the statement. To confirm the scale's reliability, a Cronbach alpha score was calculated, (a measure of the scale's internal consistency). A score equal to or greater than 0.7 is considered reliable⁵. The positivity scale created for this study received a score of $\alpha = 0.96$.

To facilitate comparison of response between different medical demographic groups, an aggregated positivity score was calculated per individual. This represents the positivity score based on thirteen statements drawn from questions 1-26, with each statement split into two parts.

The majority of the questions were divided into two parts: Part one asked participants to record their level of agreement with a stem statement at the time of completing the survey - "Currently". Part two, recorded their anticipated level of

agreement with the same stem statement for the EHCR - "Once adapted". Questions were designed in two parts to encourage the participants to set aside biases originating from the challenges of change.

The survey was launched on 5th December 2023, and was closed on the 22nd February 2024.

Results

Participant Demographics

There were 151 responses from 25 different specialties. Range of experience varied from less than one year to 30+ years of working in healthcare. (*Appendix 2 – Tables 6,7 & 8*)

Clinical Efficiency of the New Electronic Health Care System

Statements 1-26 (*Appendix 1*) covered a range of themes focusing on the day-to-day tasks required of doctors (eg. data management, communication between colleagues and primary care, safe prescribing), assessing participants' opinions on the clinical and administrative efficiency of the new EHCR. The results are tabulated in Table 1.

Table 1. Level of agreement with Stem Statements 1-26

	% Agree	% Neutral	% Disagree
STMT 1 - Time spent using Encompass exceeds the clinical benefits.	52	21	27
STMT 2 - Time spent using Encompass will exceed the clinical benefits.	36	26	38
STMT 3 - Administrative tasks are disproportionate to the clinical value.	68	16	16
STMT 4 - Administrative tasks will still be disproportionate to the clinical value.	45	19	36
STMT 5 - Accessing patient data takes less time.	27	16	57
STMT 6 - Accessing patient data will take less time.	54	23	23
STMT 7 - Recording patient data takes less time.	33	19	48
STMT 8 - Recording patient data will take less time.	53	24	23
STMT 9 - Recording patient data is more accurate and complete.	40	28	32
STMT 10 - Recording patient data will be more accurate and complete.	54	34	12
STMT 11 - Prescribing takes less time.	35	13	52
STMT 12 - Prescribing will take less time.	52	25	23
STMT 13 - Facilitates safer prescribing.	30	24	46
STMT 14 - Will facilitate safer prescribing.	49	26	25
STMT 15 - It takes less time to order tests/investigations/imaging.	34	23	43
STMT 16 - Will take less time to order tests/investigations/imaging.	53	32	15
STMT 17 - Work more efficiently in the inpatient environment.	28	26	46
STMT 18 - Will help me work more efficiently in the inpatient environment.	50	31	19
STMT 19 - Work more efficiently in the outpatient clinic environment.	10	43	47
STMT 20 - Will help me work more efficiently in the outpatient clinic environment.	25	51	24
STMT 21 - Improves the quality of patient handovers.	32	34	34
STMT 22 - Will improve the quality of patient handovers.	42	37	21
STMT 23 - Improves communication between hospital departments.	42	29	29
STMT 24 - Will improve communication between hospital departments.	60	27	13
STMT 25 - Improves communication between primary and secondary care.	9	29	62
STMT 26 - Will improve communication between primary and secondary care.	34	34	32



At the time of survey completion, 29% of participants agreed that the new EHCR had made improvements in any of the areas explored in the statements 5-26. However, 48% agree that with time it will lead to an improvement in these areas. In comparing the percentage of responses between “currently” and “once adapted”, there was a positive trend in all of the % agrees, and a negative trend in all of the % disagrees ($p < 0.0005$). This suggests that participants have a positive attitude towards the potential of the new EHCR. However, 21% of participants believe that even with adaptation, the system will still have limitations that prevent it from delivering the expected improvements.

Administrative tasks

30% of the participants agreed and 53% of the participants disagreed that the new EHCR has resulted in less time being required to access and record patient data. 45% believe that the administrative tasks required of doctors will continue to be disproportionate to their clinical value.

Regarding ordering tests and investigations, initially 34% of respondents agreed that this takes less time. With anticipated adaptation, this rises to 53%, however, 47% are still not convinced.

35% of participants thought that prescribing took less time with Epic, with 52% believing it will take less time to prescribe ‘once adapted’. Regarding prescribing safety, 30% of participants thought that Epic made prescribing safer in comparison to prior EHCRs, with 49% believing it will become safer ‘once adapted’.

Communication

60% of participants believe that Epic will ultimately improve interdepartmental communication in comparison to the previously available systems.

Despite this, the majority do not believe that the new system will improve quality of patient handovers, and only 34% agree that Epic will eventually improve communication between primary and secondary care. During the initial transition phase, this had the most negative response with only 9% of participants agreeing with the statement “Currently, Epic has improved communication between primary and secondary care”.

Overall efficiency

The majority of participants believe Epic has not improved their clinical efficiency. Regarding inpatient care, 50% of the participants believe that efficiency will improve with Epic. However, for outpatient work, only 25% of participants think that efficiency will improve with time and adaptation.

However, 55% agreed that Epic will enhance patient care once adapted.

Concerns

The participants were given a list of concerns to choose from (Table 2). 53% of participants were evenly split between

‘extra administrative work’ and ‘uncertainty whether actions have been recorded/ordered’. Regarding their major concerns, a third concern was that Epic gives less time for doctors to do the tasks they are trained to do.

28% of participants claimed that if they could, they would go back to the system they previously used (Table 3). Regarding systems these participants were using previously, 64% used another EHCR.

Table 2. Greatest Concerns about Epic

	Greatest Concern about Epic (nbr. of participants)
No concerns	13
Extra administrative work	40
It gives me less time to do the tasks I was trained to do	35
Uncertainty whether actions have been recorded/ordered	40
Extra time spent managing my inbox/basket	3
Other	20

Table 3. Breakdown of participants with a preference to revert to previously used systems

	% of Participants
Consultant	33
Specialty Doctor	19
ST/CT/IMT	21
FY1/FY2	17
Medical student	10

Demographics comparisons

Comparison between Consultants and Foundation Year Doctors

Regarding Epic overall, foundation doctors were more positive than consultants ($p < 0.0001$).

Comparison between Doctors in Medicine and Surgery

There was no difference in positivity between consultant physicians and surgeons ($p > 0.05$), with a ‘currently’ positivity score of 22 for physicians and 29 for surgeons, and a ‘once adapted’ score of 39 and 35 respectively. Majority of medical staff already used the EHR ‘EDAMS’ before Epic, but positivity towards Epic did not differ between users and non-users ($p > 0.05$).

Impact of the new EHCR on Staff Wellbeing and Education (Table 4)

66% of participants stated that the new EHCR adversely

Table 4. Impact on Wellbeing

	% Agree	% Neutral	% Disagree
STMT 28 – Increased stress levels at work.	66	14	20
STMT 29 – Increased stress levels at home.	39	25	35
STMT 30 – Difficult to separate personal life from life as a doctor.	24	28	48
STMT 31 – Work is more satisfying.	14	36	50
STMT 32 – Feel on edge.	46	22	32

affected their stress level at work, with 46% of doctors feeling more on edge since the new system's introduction. In addition, 39% participants stated that their stress levels at home were also adversely affected. 14% of participants have found work to be more satisfying since introduction of the new EHCR.

Medical education has also been affected with 67% of participants agreeing that there is less time for both medical student education and postgraduate training.

Discussion

Patient Care and Safety

The GMC's Good Medical Practice states that a doctor must place patient care at the centre of their practice⁶. These findings must be assessed in that context. In this study, 55% of participants believe Epic will ultimately enhance patient care, 45% have concerns it will not.

Accessing Patient Data

EHCRs have perceived advantages over paper-based notes, which can be disorganised, illegible, difficult to interpret, and are often misplaced. Conversely, EHCRs provide patient information on a single platform providing readily accessible patient data that is comprehensive and complete, thus improving clinical decision making and patient outcome. Previous studies have suggested that having patient information on one system enables doctors to deliver care in a safer and more efficient way⁷. Specifically regarding Epic, participants provided free-text answers such as:

"It keeps a complete record of patient care in one place, accessible from everywhere"

"Easier to read compared to written notes which tend to be incomplete."

"Epic is much better than the previous system with all critical patient information easily accessible"

"The notes are easier to understand, no handwriting required. More detailed"

Others highlighted downsides regarding EPIC usability, expressing concerns about its negative effect on doctor-patient relationships.

"Half the session is spent trying to find the patient notes"

"Everything is taking longer"

"Not intuitive"

"It is not user friendly, and nothing is self-explanatory"

"Doctors are being significantly distracted from face-to-face patient care"

Previous papers demonstrated that more time on computers left less time for direct patient interaction. "For every hour physicians provide direct clinical face time to patients, nearly two additional hours are spent on EHR"⁸, with a negative effect on patient care. Given that our study demonstrates a positive trend between how participants feel currently and how they anticipate feeling once adapted, it may suggest that some negativity relates to the challenges of change.

EHCRs have also been criticised for having excess information on one screen. These screens are deemed not intuitive, too cluttered and difficult to navigate, making data interpretation more challenging. This may have a negative impact on patient care. The increased cognitive load placed on doctors as a result of these systems can result in fatigue, leading to errors⁷. Regarding Epic, difficulties relating to interpretability were raised by the participants.

"High level of stress about catching all the results/information that we should be seeing"

"Complex system. Difficult to read bloods, medications - easy for serious errors to go unnoticed"

"Can easily see fluid balance and drain charts on paper whilst assessing patients - this is extremely difficult to see and interpret on encompass"

Recording Patient Data & Recording Actions

Following introduction, time taken to record patient data and record actions is predicted to be an improvement from previous systems. However, 48% of participants disagreed with the statement: "Currently, recording patient data takes less time with Epic" and 43% disagreed with: "Currently, ordering tests and investigations takes less time with Epic". Criticism of the training (Encompass) which was frequently expressed in free text could explain these findings.

Prescribing

Epic should facilitate safer prescribing with an alert system which highlights comorbidity, allergies and warning of possible contraindications and drug interactions prior to prescribing⁴. However, participants raised concerns that excessive information may lead to more safety incidents.



“Too many medication adverse effects suggestions on medication prescribing, most of which are unnecessary suggestions. A lot of the time we end up ignoring the most important ones. This is not safe!”

“Prescribing is very unsafe. Too many alerts and therefore now automatically overriding without reading properly”

There should be no training curve with prescribing, particularly as there is good evidence that EHCRs do reduce prescribing error rates. Clinical decision support has been acknowledged to contribute towards this, as well as the removal of written illegibility⁹.

Nonetheless, studies confirm that serious prescribing errors are not eliminated with EHCRs. Research has suggested that the key to improving this is through early recognition of these issues with early action, achieved through system redesign and user training¹⁰. This should be an area of focus for Epic and Encompass.

Communication

Communication between hospital departments received a positive response from participants, with 42% agreeing this has already been an improvement and 60% anticipating that Epic will result in improved communication once adapted. Others have shown that EHCRs contribute towards improved communication¹¹.

Communication between primary and secondary care had one of the most negative responses, with only 34% of doctors agreeing that Epic will eventually improve communication between primary and secondary care ‘once adapted’. Currently, only 9% of participants agree with the statement that “Epic has improved communication between primary and secondary care”.

General Practitioners (GPs) are not currently using Epic. GPs have access to Epic via an Epic care link where they can view their patients’ records¹², however poor interoperability (the ability of different EHCR systems to communicate with each other)¹³ has been acknowledged as a significant weakness of EHCRs. Lack of interoperability is shown to potentially result in transmission of incomplete patient data, medication errors, and iatrogenic harm as a consequence of uncertainty¹⁴. Given that GPs are not expecting to implement Epic, interoperability concerns will remain. Therefore, potential solutions to ameliorate this concern are required.

Overall Efficiency

72% of participants did not report any improvements to inpatient clinical efficiency since introduction of Epic. However, 50% of doctors believe this will change with time. In contrast to inpatient efficiency, outpatient care received a negative response, only 25% believe that efficiency will improve with time and adaptation.

Participants remain pessimistic regarding outpatient

efficiency, suggesting that the initial reduction in activity and efficiency is likely permanent. It is possible that the anticipated negative views reflect the current adjustment difficulties being experienced by doctors in outpatients. Alternatively, it may be that the inherent nature of outpatients reveals inherent limitations of Epic. Or it may simply reflect the time-consuming burden of added administrative work placed on medical staff in outpatients, due to the requirements imposed by Epic.

Burden on Staff

Admin

A consequence of Epic for doctors appears to be “extra administrative work”. Extra administrative tasks with EHCRs place an additional burden on doctor workload. Previous studies have demonstrated that doctors experience dissatisfaction and frustration in their work occasioned by the extra administrative demands, and time to undertake those demands, which they perceive takes time away from direct patient care.¹⁵ In this study dissatisfaction was highlighted by the following comments.

“Too much admin for clinical staff, waste of resource”

“A perfect system would have doctors freed up to do what we’re trained to do...”

“Encompass is not intuitive; it is heavily dependent on doctors to work. Doctors who don’t have the time to administrate”

“Time is now consumed with clearing basket inbox and less time with primary caring role.”

“Spending excess time on admin, doing work my secretary formally did. Less time to focus on patients.”

“More time on administrative tasks that were previously done by dedicated admin staff”

Only 14% of participants found work to be more satisfying since the introduction of Epic. Research from Denmark shows persistent dissatisfaction with Epic, five years after its introduction, with 32% of participants in their study remaining dissatisfied. Usability issues with Epic were identified as a significant factor contributing to this dissatisfaction¹⁶.

In this study, concerning, 45% believe that the administrative tasks required by Epic will continue to be disproportionate to the clinical value.

Impact on Medical Education

Regarding the impact on medical training, feedback was negative. 67% of participants stated that they had less time for medical education and training (undergraduate and postgraduate). The comments perhaps provide insight into why this is the case.

Comments from medical students:

“Doctors are spending all their time figuring out

encompass and therefore have no time for students. No spare time to teach us."

"Students seeing fewer patients due to the cut down in patient numbers and therefore getting less clinical exposure."

Comments from trainee doctors:

"More time spent on admin when I could be learning more about the specialty"

"Due to poor training received on encompass, I have spent more time helping my seniors learn how to use the app rather than the other way around."

"For the last 2 months there has been no teaching for medical trainees (...) encompass sessions which are useless and do not actually help with using the system. Either these sessions should be useful, or we could have just had our usual medical teaching"

Comments from medical staff:

"Spending so long working through bulky system for admissions and ensuring that everything clicked is accurate that we're unable to fully engage with students and help them learn."

"Using encompass consumes so much time and it is difficult not to make it the focus of the clinical encounter. Time between cases/appointments is spent completing complex series of admin tasks instead of talking to trainee/student"

"Encompass has created additional tasks for clinicians and people being more stressed has a negative impact on their willingness and ability to provide training"

The key message is that time for teaching is lost during consultation, as a result of the administrative burdens brought on by Epic combined with the challenges of adapting to the new system.

Stress and Burnout

Resistance to change or age is frequently given as a reason for negative impressions with blame often placed on the staff. Adjustments can be challenging, therefore the impacts of the significant change to a new EHCR needs to be carefully managed before and during the process. This study showed that 66% of participants found that the new EHCR adversely affected their self-reported stress levels at work. Of more concern, 39% of participants experienced increased stress levels at home.

Comments from doctors are particularly jarring:

"I am so stressed. I want to hand in my notice"

"If I knew working as a doctor would be a stressful as this, I never would have done medicine"

"So upset about work every day"

"Dread the thought of coming to work. Fear the mistakes that are being made"

"Destroys my enjoyment of a job that I love"

There does not appear to be one specific reason for this negative personal impact. It is established that increased admin, usability difficulties, increased time requirement, and fatigue (raised as concerns by participants), contribute to professional dissatisfaction, stress and burnout. Previous papers suggest that dissatisfaction with EHCRs can result in reduced motivation and further promote burnout⁷.

The reasons behind these comments are not clear. They could be attributed to the increased workload secondary to administrative tasks; or simply the fact that Epic can be accessed 'anywhere at any time', facilitating the ease of bringing work home; or may indicate concerns over patient care about which the doctor "takes home with them".

Importantly we know that stress and burnout have implications on health care delivery, such as increased frequency of medical errors, low productivity, patient dissatisfaction, poor outcomes, and ultimately, job dissatisfaction. All of which also results in, increased sick leave, absences, increased staff turnover, early retirement, notwithstanding the financial costs of poor care¹⁷. When introducing such systems, we must be aware of these concerns, listen and seek solutions by working together with staff to ensure patient safety.

Adaptation

Overall, there was a positive change in all the % agrees, and a negative change in all the % disagrees regarding "currently" versus "once adapted", suggesting that the potential of Epic to deliver better care is recognised, but not universally acknowledged. A longitudinal study is required to ascertain whether the problems currently being experienced are due to the challenges of adaptation and resistance to change, the consequences of administrative shift to the medical staff or perhaps poor training with Epic. Determining these contributing factors is important in terms of facilitating the transition to Epic in the remaining trusts in addressing concerns going forward.

Training

Inadequate training and preparation (Encompass) were identified by many participants as a factor making adaptation to the new system more challenging.

"Poorly trained, poorly planned, no discussion with clinicians on the ground before decisions were made"

"it was pushed out too quickly instead of in phases"

"Potential to be useful. Although a lot of work is required to improve it. More training should've been provided."

"I do agree with an online system, however it is causing an immense amount of stress especially when working"



in a high-pressure environment. More needs to be done in order to improve this, including better training and support for staff”

Other studies have also recognised that inadequate training is a contributing factor to making transitions to new EHCRs more challenging. In addition to adequate training, involvement of the clinician in the design of the EHCR relevant to their specialty has also been identified as helping adaptation.¹⁸ It is surprising that given Epic has been introduced elsewhere in the UK, lessons learnt from that introduction were not addressed in training.

Attitude

Others have demonstrated that to build positive mindsets in healthcare, strong institutional leadership and supportive culture is ultimately what is required, emphasising the importance of management working with staff. Without these foundations, change will always be more difficult¹⁸.

Experience

Prior experience with electronic systems did not affect a doctor's ability to adapt.

Stage of medical training is another factor to consider regarding its influence on attitudes and adaptability towards EHCRs. A difference was observed between Foundation doctors and Consultants. Foundation doctors had an overall more positive response. This could also be explained by foundation doctors having less responsibility in comparison to consultants and work predominantly in the inpatient setting, a different environment to clinics, theatre and day procedures.

Limitations

There are limitations to our work. This observational preliminary study assesses implementation and perceived potential of a new EHCR system. A longitudinal study is required to determine the accuracy of the participants' anticipated responses once adapted.

Responses were limited by the time frame of the study, the coinciding of the study with the holiday season, and scepticism from doctors regarding the study's impact. It must be taken into consideration that the survey was voluntary, therefore doctors completing the survey may be those with stronger opinions and this may not reflect the attitudes of all doctors working for the trust.

While this study was attributed to quantifying responses, it was often the free text that provided the real time insight into the advantages and disadvantages of the new system.

We are not able to address in depth why doctors may not like one of the world's best and most expensive EHCRs. However

the reality would appear that these systems are not primarily designed around doctors and therefore the lived reality of using them is not to be unexpected. What is evident however are the opinions expressed regarding EHCR's potential to change care in a positive way amongst all groups.

The aim of this paper was to present a balanced evaluation of the introduction of an EHCR. However the data collected did not allow a more in-depth analysis of both the negative and positive responses. In the literature there are a few papers such as “Why Drs hate their computers” that present EHCRs in a different context, expressed by Atul Gawande as follows: “a system that promised to increase my mastery over my work has, instead, increased my work's mastery over me”¹⁹.

Conclusion

Despite an initial overall negative response towards EHCR, participants have a positive attitude towards its potential to improve patient care. However, this does not meet with universal agreement, and a considerable number of respondents in all categories remain concerned that the system will not meet expectations.

In essence, the immediate post-implementation experience and the anticipated “once adapted” utility does not meet the pre-implementation expectations. There is a sense that the users studied (doctors and doctors in training) primarily found themselves in a reactive mode, focused on fending off problems, managing concerns and anxiety about patient care, and exhibiting frustration with the implementation/training process and operability of Epic, rather than a proactive mode of realising the possible benefits of the system.

While we acknowledge that this a patient EHCR designed to improve patient care, more consideration must be given to the users of that system when considering future improvements in design and implementation. Concerns relating to system usability and administrative burden imposed by Epic on senior staff remain apparent throughout the study. ‘A perfect system would have doctors freed up to do what we are trained to do’.

A number of free text comments highlighted the time-consuming nature of documentation, and the potential for technology to interfere with the doctor-patient relationship. These systems, while intended to streamline healthcare, can sometimes create more work and frustration for clinicians.

Usability issues were identified as contributory to this dissatisfaction. Inadequate training was identified as a factor which made adaptation more challenging. This in particular is a consideration for organisations yet to implement EHCRs.

Appendix

*Appendix 1 - Stem Statements***Table 5.** Complete Survey Stem Statements

NUMBER	STATEMENT
STMT 1	Time spent using Epic exceeds clinical benefits.
STMT 2	Once I have fully adapted to the new system, the time spent using Epic will still exceed the clinical benefits.
STMT 3	Administrative tasks required of doctors when using Epic are disproportionate to the clinical value.
STMT 4	<i>Once I have fully adapted to the new system, the administrative tasks required of doctors when using Epic will still be disproportionate to the clinical value.</i>
STMT 5	Accessing patient data takes less time with Epic.
STMT 6	<i>Once I have fully adapted to the new system, accessing patient data will take less time with Epic.</i>
STMT 7	Recording patient data takes less time with Epic.
STMT 8	<i>Once I have fully adapted to the new system, recording patient data will take less time with Epic.</i>
STMT 9	Recording patient data is more accurate and complete with Epic.
STMT 10	<i>Once I have fully adapted to the new system, recording patient data will be more accurate and complete with Epic.</i>
STMT 11	Prescribing with Epic takes less time.
STMT 12	<i>Once I have fully adapted to the new system, prescribing with Epic will take less time.</i>
STMT 13	Epic facilitates safer prescribing.
STMT 14	<i>Once I have fully adapted to the new system, Epic will facilitate safer prescribing.</i>
STMT 15	It takes less time to order tests/investigations/imaging with Epic.
STMT 16	<i>Once I have fully adapted to the new system, it will take less time to order tests/investigations/imaging with Epic.</i>
STMT 17	Epic has helped me work more efficiently in the inpatient environment.
STMT 18	<i>Once we have adapted to the new system, Epic will help me work more efficiently in the inpatient environment.</i>
STMT 19	Epic has helped me work more efficiently in the outpatient clinic environment.
STMT 20	<i>Once we have adapted to the new system, Epic will help me work more efficiently in the outpatient clinic environment.</i>
STMT 21	Epic improves the quality of patient handovers.
STMT 22	<i>Once we have fully adapted to the new system, Epic will improve the quality of patient handovers.</i>
STMT 23	Epic has improved communication between hospital departments.
STMT 24	<i>Once we have fully adapted to the new system, Epic will improve communication between hospital departments.</i>
STMT 25	Epic has improved communication between primary and secondary care.
STMT 26	<i>Once we have fully adapted to the new system, Epic will improve communication between primary and secondary care.</i>
STMT 27	Overall, Epic will enhance patient care.
STMT 28	The introduction of the new electronic system has adversely affected my level of stress at work.
STMT 29	The introduction of the new electronic system has adversely affected my level of stress at home.
STMT 30	I find it difficult to separate my personal life from my life as a doctor since the introduction of the new electronic system.
STMT 31	My work as a doctor is more satisfying since the introduction of the new electronic system.
STMT 32	Since introduction to the new electronic system, I feel on edge.
STMT 33	If it was up to me I would go back to the old system.
STMT 34	The introduction of Epic has resulted in less time being available for medical education and training.



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Appendix 2 - Cohort Demographics

Table 6. Participants' level of training

Level of Training	Number of Participants
Consultant	45
Specialty doctors	16
Trainee doctors (IMT,CT,ST)	33
Foundation year doctors	35
Medical students	22

Table 7. Participants' years of experience working in healthcare.

Years of Experience	Number of Participants
30+	12
16-29	31
6-15	34
1-5	25
Less than 1	27
Medical student	22

Table 8. Specialties that participated in the survey

Specialties = 25	General medicine, Respiratory, Cardiology, Gastroenterology, Nephrology, Endocrine, Haematology, Rheumatology, Dermatology, Geriatrics, Stroke, Psychiatry, Emergency medicine, Intensive Care Medicine, Obstetrics & Gynaecology, Paediatrics, Neonatology, General surgery, Colorectal surgery, Urology, Trauma & Orthopaedics, Plastics, ENT, Anaesthetics, Radiology
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Clinical Paper

The Neurological Practice of an African District General Hospital

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Abstract

Objectives

Whereas about 20% of emergency medical admissions in richer countries are neurological, the situation in poorer countries is less clear. To help clarify this we studied admissions data in a hospital in Nyala, Sudan and compared our findings with the results from a previous, methodologically similar study from Northern Ireland (NI).

Methods

Over three months the numbers of emergency medical admissions to Nyala Teaching Hospital were recorded, along with the percentage with neurological symptoms. The following information was also noted: diagnosis, mortality, the use of investigations, and referral to neurologists and neurosurgeons. The results were compared to a study from the Downe Hospital, NI carried out in 1987.

Results

Fifty-six (24%) of 234 medical admissions were neurological. Stroke (57%), infections (21%) and tumours (11%) made up 89% of neurological admissions, with epilepsy accounting for only 4%, a pattern quite different from the NI study. Mortality was 23% compared with 12% in the NI study. Referral to neurospecialists was similar.

Conclusion

Although emergency neurological admissions were slightly commoner, the most striking difference between Nyala and the NI study was the high proportion of stroke admissions in Nyala to the near exclusion of other neurological conditions. The first priority to improving neurological care in Nyala, (and by implication, sub-Saharan Africa), is a stroke prevention program.

Key Words: Health services, Sub-Saharan Africa, Hypertension, Sudan, Stroke

Introduction

In 1987 one of us published a paper documenting the neurological contribution to acute medical admissions at a small district hospital in Northern Ireland, UK¹. This

found that 19% of these admissions were neurological and provided evidence supporting the expansion of neurology as a specialty in the UK². This was at a time when the number of UK neurologists was much smaller than it is today.

The situation in Africa now has some similarities with the UK in 1987 with few neurologists, often working from regional centres many miles from where much of the population lives. We thought that it might be opportune to repeat the study undertaken in NI in a district general hospital in Sudan. Our aim was to examine the similarities and differences of patients admitted, and to determine whether our findings would inform the development of local neurological care in Nyala.

Methods

Location and facilities

The study was undertaken in Nyala Teaching Hospital (Figure 1) in Nyala city, the capital of South Darfur State in Sudan in sub-Saharan Africa. This is a public hospital serving



Figure 1. Nyala Teaching Hospital

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a population of about 2,700,000. There is another public hospital in Nyala, the rest being private. It is situated about 760 miles from Khartoum, the capital of Sudan, where all the regional specialties, including neurology and neurosurgery, are to be found. The hospital has 300 beds and provides emergency and inpatient services in general medicine, general surgery, obstetrics and gynaecology, and paediatrics. There are also outpatient clinics in chest medicine, ophthalmology, dermatology, psychiatry, oncology and ENT surgery, but there is no visiting neurologist. There are 52 beds in general medicine looked after by six physicians helped by 12 registrars and six house officers. Plain radiology, CT scan, and basic CSF analysis are available for the investigation of neurological patients within the hospital. MRI is available by arrangement elsewhere in the city. EEG, EMG and nerve conduction studies are only available in Khartoum.

Data collection

This was a prospective study over a three-month period starting in February 2020. The study was completed before Covid-19 affected hospital admissions in Nyala. The methodology was identical to that used in the study from Northern Ireland. New admissions to the medical wards at Nyala Hospital were screened by two of the authors (SMK and AAA) each day. Admissions under 12 years of age were excluded as were patients with malaria. Patients in whom a neurological condition was either the primary reason for admission, or an active contributing factor, were identified and their case notes reviewed. There was no electronic coding of diagnoses at Nyala Hospital. Information on age, gender, diagnosis, investigations, and referrals was collected and added to a spreadsheet

Results

Patients admitted

Two hundred and thirty-seven patients were admitted to the medical wards, 56 (24%) of whom had neurological diagnoses.

Neurological diagnoses

These are shown in Table 1.

DIAGNOSIS	NUMBER	%
Stroke or TIA	32	57
Brain infections	12	21
Brain masses	6	11
Epilepsy	2	4
Dementia	1	2
Transverse myelitis	1	2
Chorea	1	2
Cerebral venous sinus thrombosis	1	2

Table 1. Neurological diagnoses in Nyala (n=56).

Of the 31 cases of stroke, the mean age was 65 years, range 35 - 85 years. All patients had CT scans of the brain which showed 18 infarcts (58%) and 13 haemorrhages (42%). Hypertension was present in 15 (48%) and diabetes mellitus in eight (26%).

Brain infections consisted of four cases of meningitis - two bacterial and two tuberculous - and seven with meningoencephalitis - two presumptively due to Herpes simplex and the others unknown. There was one patient with brain abscess, who responded well to antibiotics.

In total, 39 CT scans, 9 MRI scans and two lumbar punctures were performed.

Three patients were referred to a neurologist - meningioma (1), epilepsy (1) and venous sinus thrombosis, and three to a neurosurgeon - meningioma (2) and unidentified brain mass (1).

There were 13 deaths overall (23%).

Comparison with UK study

The frequency of each diagnosis during the studies are shown in Figure 2.

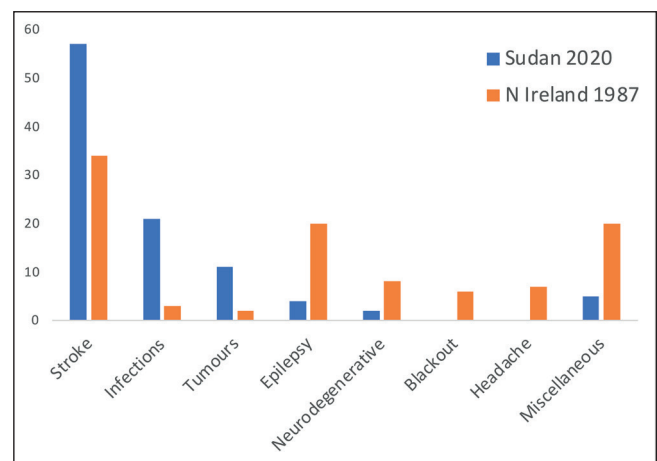


Figure 2. Comparison of main diagnosis at each hospital as a percentage of all neurological admissions

There were many more strokes in Nyala making up over 50% of admissions and a bigger proportion of the total bed stay. CNS infections were also commoner in Nyala (23% v 3%) as were tumours (11% v 2%). Admissions for epilepsy were very much fewer in Nyala (4% v 21%) and there were no admissions there for investigations of headache or loss of consciousness or for unexplained neurological symptoms. Deaths overall were 23% in Nyala compared with 12% in NI. Referrals to specialist neurologists and neurosurgeons was broadly similar (11% and 8%).

Discussion

Our results show that neurological symptoms make up a substantial proportion of acute medical admissions to a district general hospital in Sudan - 24% - higher than the 19% found in the earlier NI study when availability of neurological services in the UK was similar to Sudan today.

Stroke is the dominant neurological disease in Nyala making up 57% of admissions and a considerably higher proportion of bed-days. We did not study stroke risk factors systematically, but over half of stroke admissions had hypertension and the finding of 42% with haemorrhage on CT scan, as opposed to infarction, suggests that the prevalence of hypertension may be higher, since hypertension is a greater risk factor for haemorrhage. In a study from Eastern Sudan, 41% of a population sample had hypertension, 82% of whom were undiagnosed³.

Otherwise, CNS infections were more common in Nyala which is not surprising. The prevalence of HIV is generally low in this part of Africa and only a single patient in this study tested positive. We also excluded patients with malaria from the neurological cohort; there were 12 admissions with this over the three-month study period.

All other conditions were encountered with a lower frequency than in the NI study and some, such as headaches or blackouts, were not admitted at all. Perhaps the most surprising difference though was the reduced number of people with difficult epilepsy admitted. It may be that epilepsy is regarded as a spiritual rather than a medical problem⁴ but this was a difference which surprised us and one which requires an answer given the high mortality from untreated epilepsy⁵. It is unlikely that epilepsy patients would have gone elsewhere as there are no EEG services locally.

There have been a number of other studies of neurological hospital admissions in different African countries⁶⁻⁹. Their methodologies are different so they are difficult to compare exactly. One from Uganda showed a stroke prevalence of 27%⁶, and two studies from Nigeria showed had a stroke prevalence of 24%⁷ and 42%⁸, of all neurological admissions. In the Uganda study, stroke was the major cause of in-hospital mortality. A study from the Democratic Republic of Congo was however different with stroke accounting for only 7% of admissions at a rural hospital⁹.

Obviously, there is uncertainty about whether this sample of neurological care is typical of Sudan as a whole and this is a weakness of this small study. However, based on our knowledge of healthcare in Sudan, we have no reason to believe that the situation in Nyala is atypical and, by inference, it is also likely to be representative of the situation across much of adjacent sub-Saharan Africa.

Conclusion

The major message of this study is that most of the neurological workload of this African hospital is due to one largely preventable condition - stroke. This is quite unlike the message of the previous study from the UK which was that more neurologists were needed at district general hospitals to cope with the variety of neurological conditions seen there. Here, the overwhelming need is for a public health campaign to prevent stroke, principally by controlling raised blood pressure. We are not the first people to have pointed out this need in Africa¹⁰⁻¹²; public health campaigns to treat hypertension are not straightforward. Blood pressure control is effective but it is not easy to explain the need for it to patients, measure it, or fund any necessary treatment for it. In a recent Sudanese study half of treated patients had poor blood pressure control due to poor adherence¹³.

If stroke admissions were reduced then hospitals would be better placed to deliver services for patients with other neurological diseases such as epilepsy, who might benefit from their services.

Postscript (AKM)

In April 2023 a war between the Sudanese army and a heavily-armed Rapid Support Force started in Sudan. Due to this war our lovely town Nyala, capital of South Darfur, has been affected. Much infrastructure has been destroyed including the hospitals. Water and electrical supplies were damaged. Many civilians were killed. Many people were displaced to more safe areas in the country and others escaped to neighbouring countries. Major hospitals have ceased working because of the damage that has happened, the lack of security, and the absence of supplies. Many of our colleagues moved to other places in Sudan where the conflict was less than in our town. Now Nyala Teaching Hospital is working again but with limited capacity with great efforts from volunteers and NGOs, and is providing health services to the people who have returned to the town. My colleague Asim and I were working as medical registrars in our final year and preparing for the MD examination, when the war began. We struggled to move to safer area with our families. Seven months without a job and financial support was a very difficult time for us. Finally, with our patience and dedication, we hold a clinical MD in internal Medicine and are now working in Chad.

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Contributors VP conceived the article and wrote the manuscript draft. SMK and AAA were involved in the clinical care of the patients. All authors critically reviewed the manuscript for intellectual content and edited the article.



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Patient consent for publication Not applicable.

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Clinical Paper

“Now you’re talking my language” - Improving health literacy and patient-directed knowledge of scientific abstracts through provision of plain language summaries created by artificial intelligence: A cross sectional infodemiology study

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SCIENTIFIC ABSTRACT (Author Written)

Background

Due to free and digital availability of scientific abstracts in medical journals, as well as search engines including PubMed, many patients are increasingly looking to these as reliable and trusted sources of information, amidst an information ecosystem of potential mis- and disinformation. However, such scientific abstracts are difficult-to-read by the lay community, as they are not written purposefully for a lay audience. The Plain Language Summary now offers such readers a new medium to engage with, thereby helping with their health literacy and understanding of the research findings being described. The aims and objectives of the present study were to: calculate the readability of all scientific abstracts published in the *Ulster Medical Journal* over the five year period 2020 – 2024 (n=48), (ii) using artificial intelligence, prepare a plain language summary of each scientific abstract (n=48) with (a) minimal prompts and (b) with extensive prompts and (iii) calculate the readability of AI-generated plain language summaries.

Methods

Readability was calculated using Readable software, defined by the (i) Flesch Reading Ease (FRE), (ii) Flesch-Kincaid Grade Level (FKGL), (iii) Gunning Fog Index and (iv) SMOG Index and four text metrics [word count, sentence count, words/sentence, syllables/word] on abstracts from all original clinical papers (n=48) published in the *Ulster Medical Journal* in the last five years (2020-2024). Plain language summaries were created from the existing scientific abstract using artificial intelligence with (a) minimal prompts and (b) extensive prompts. The readability of all AI-created plain language summaries was further determined.

Results

Scientific abstracts had a mean FRE and FKGL score of 24.2 ± 14.1 (standard deviation) and 14.4 ± 2.8 , respectively (Reference target values of ≥ 60 and ≤ 8 , respectively). AI created plain language summaries with improved readability

scores of 59.8 ± 7.4 and 8.9 ± 1.6 , respectively for summaries with minimal prompts, thereby almost meeting reference readability targets. AI-created summaries with extensive prompts had mean readability scores of 71.3 ± 6.1 and 6.3 ± 0.9 , respectively, with 46/48 (96%) of scientific abstracts now reaching reference readability target values. Scientific abstracts and Plain Language Summaries were statistically different ($p < 0.0001$) in terms of both FRE and FKGL scores. Inputting the necessary and appropriate prompts to the AI-tool is critical to attaining the desired readability values.

Conclusions

Medical journals may reach out to lay readers, including service users, patients, family and friends, through new innovation with the inclusion of a Plain Language Summary. Scientific abstracts are written at a level which is beyond the average reading age of 11 years old in the UK. Computational creativity through the employment of AI platforms can successfully generate narrative text for specific reading ages, with optimal readability. Effective communication of medical research findings from medical and scientific papers is vital for service users to enhance their health literacy, thereby helping promote better clinical outcomes, as well as promoting inclusivity for lay readers. With thorough checks and controls by the authors of clinical papers, AI-created plain language summaries may provide

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a new medium for medical journals to communicate with patients and service users, the results of clinical and original studies. The ability to create fit-for-purpose and easy-to-read Plain Language Summaries allows the lay public and service users to now become included in the family of readers of the journal and further supports the health literacy of patients and service users.

Keywords: health literacy; patient education; patient-centred care; plain language summary; readability.

PLAIN LANGUAGE SUMMARY (AI-Generated)

Making Science Easier to Read: Can AI Help?

What was the purpose of the study?

Scientific papers often use very hard words. Many patients try to read these papers online, but the language is too complex. This makes it hard for them to understand important health information. A new idea is to add a Plain Language Summary. This is a simple version of the Scientific Abstract. The aim of this study was to firstly check if abstracts published in the *Ulster Medical Journal* were easy-to-read for the general public. The researchers also wanted to test if artificial intelligence (AI) can write summaries which are more readable.

What did the researchers do?

The team looked at 48 research papers published in the journal between 2020 and 2024. They used a computer tool to test how readable the abstracts were. They then asked AI to write plain summaries of each abstract. AI was tested in two ways: with very little guidance, and with lots of detailed instructions. The readability of all AI summaries was then measured.

What were the findings of the study?

The original abstracts were very hard to read, far above the UK average reading level of an 11-year-old. When AI was given only a small amount of guidance, the summaries became much easier to read, but were not always simple enough. When AI was given more guidance, the summaries became even clearer. In fact, almost all of the 48 papers reached the target for easy reading.

What does this mean?

Scientific papers in medical journals are too difficult for most patients to understand. But AI can help by creating easy summaries. These summaries let patients, families, and the public take part in reading and learning from new research. With the right checks, this could improve health knowledge and help people feel more included.

Introduction

Individuals need adequate literacy skills in order to understand and navigate healthcare systems. They also need health literacy skills which will allow them to make informed decisions about their healthcare.¹ The World Health Organization (WHO) has defined health literacy as “

...the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health.”¹ Health literacy is about how people understand information relating to health and healthcare, and how they apply that information to their lives, use it to make decisions and act on it.¹ According to the WHO, the impact for individuals with low levels of health literacy may include (i) significantly more negative outcomes across a range of health indicators, (ii) more likely to have unhealthy lifestyles, (iii) less likely to make informed healthy lifestyle choices and engage with preventative programmes, (iv) higher levels of illness and preventable premature mortality, (v) less able to manage long term conditions and (vi) less likely to adhere to medication regimes effectively.^{1,2}

A 2015 Public Health England commissioned report entitled “*Improving health literacy to reduce health inequalities*”³ highlights the extent of the health literacy challenge. It identified that up to 61% of the English working age population do not routinely understand health and wellbeing information they are given.

In Northern Ireland, health literacy was one of the key themes in *Making Life Better*, the Department of Health’s 10-year public health framework.⁴ Recent data from the 2023/2024 Health Survey Northern Ireland showed that just over one fifth of people interviewed found it difficult to make decisions to improve their health and well-being.⁵ Of these, most notably were respondents from the most deprived background, as well as those from an urban environment.⁵ In 2021, the Northern Ireland HSC Patient and Client Council published a report entitled “*Towards an action plan for health literacy in Northern Ireland A Patient and Client Council scoping paper*”⁶ whose objective was to (i) establish the current context of health literacy in Northern Ireland and in the wider UK, (ii) collate evidence on the importance of health literacy, (iii) provide evidence on the scale of the issue for different sections of the population and (iv) review specific interventions for improving health literacy. Recommendations from this report included promoting effective communication through improving how health information is communicated.⁶

It is hoped that data from the current study will help identify gaps and promote innovative ways of communicating research findings to the lay audience, to support and enhance health literacy with Northern Ireland service users.

Many authors of scientific, clinical and research papers find scientific communication with the lay audience challenging.⁷⁻¹⁰ There are several potential reasons why this is so, including academic training, where authors are trained to be succinct and concise, employing specific scientific and medical terminologies.⁷⁻¹⁰ Additionally, many are fearful of oversimplifying their written work, especially for lay audiences, as this may be perceived to dilute out the science

or distort or misrepresent what the authors are trying to say and convey to the reader.⁷⁻¹⁰ Furthermore, there is the so-called “curse of knowledge”, which is a cognitive bias, where authors assume the readers have the same background information and understanding as they do, even when most often, they do not.⁷⁻¹⁰ One solution to this is the Plain Language Summary (PLS). While not replacing traditional abstracts, plain language summaries are where authors are expected to communicate their research in less-technical ways that would appeal to new audiences.¹¹ Artificial intelligence (AI) tools are now widely available which can help authors write for a lay audience. Recently (April 2025), McMinn and colleagues performed extensive studies between large language AI generators and the medical writer, for the generation of plain language summaries (PLSs). In Study 1, bespoke AI PLSs were easier to read than medical writer PLSs across all readability metrics ($p < 0.01$).¹² In Study 2, bespoke AI output saved medical writers >40% in time for PLS creation and required less effort than unassisted writing. Subject matter expert-assessed quality was higher for AI-assisted PLSs, and physicians preferred bespoke AI-generated outputs for patient use.¹² In Study 3, bespoke AI PLSs were more readable and rated of higher quality than medical writer PLSs. Overall, this study concluded that the bespoke AI process may enhance access to health information by helping medical writers produce PLSs of scientific content that are fit for purpose.

Furthermore, several healthcare regulators, including the General Medical Council (GMC) and the Health and Care Professions Council (HCPC), acknowledge the benefits that AI can offer to patient care and have offered up specific guidance on how best to use AI tools within the professional practice of their registrants. With the GMC guidelines, AI tools are not regulated, more so, employment of such tools by doctors in terms of professional responsibility, accountability, training and competence, places the onus on the clinician to use their professional judgement, as well as verifying the accuracy of AI-generated outputs. With the HCPC, the regulator urges registrants and education providers to remain aligned with standards and to critically appraise emerging technologies in the context of safety, ethics, and professional integrity.

Readability is a measure of how easy a piece of text is to read and has become an important measurable parameter within healthcare, particularly when trying to assess how well patient-facing written material has been prepared. Readability is assessed using established evidence-based formulae quantifying words per sentence, syllables per word, as well as other syntax parameters. Readability formulae commonly quoted in healthcare analysis include the Flesch-Kincaid Grade Level (FKGL) and the Flesch Reading Ease (FRE) scores.¹³ To date, there has not been any analysis conducted that has compared the readability of scientific abstracts published in the *Ulster Medical Journal* and Plain Language Summaries of the same abstract. If

scientific abstracts have poor readability, then patients may be less likely to understand the research being undertaken and discussed. Examples of this may include that a good understanding of medication information is therefore vital for an individual to adequately comprehend and be compliant with post-procedure requirements, in a way to maximise health outcomes and clinical success of the medical procedure/treatment, as well as helping improve clinical trial involvement.

The aims and objectives of the present study are to:-

- (i) Calculate the readability of all scientific abstracts published in the *Ulster Medical Journal* over the five year period 2020 – 2024 ($n=48$);
- (ii) Using AI, prepare a plain language summary of each scientific abstract ($n=48$) with (a) minimal prompts and (b) with extensive prompts;
- (iii) Calculate the readability of AI-generated plain language summaries.

Methods

Retrieval of Scientific Abstracts

Scientific abstracts ($n=48$) were obtained from the *Ulster Medical Journal*, from all *Clinical Papers* published in the last five years (2020, $n=5$; 2021, $n=12$; 2022, $n=9$; 2023, $n=14$; 2024, $n=8$). Full *Clinical Papers*, including each of their abstracts were obtained from the journal's website (<https://www.ums.ac.uk/journal.html>). All papers and their abstracts were freely available to the public and in the public domain.

Preparation of AI-generated Plain Language Summaries (PLS)

Each abstract was copied from the UMJ website into Microsoft Word and data-cleansed, including the deletion of extra spaces and correcting any formatting errors, due to the copying process. AI-generated Plain Language Summaries were created in this study using ChatGPT 5.0, employing a standard PC computer with access to the internet. No specialised training was necessary to use this AI platform, apart from following given prompts and instructions from the AI-platform. ChatGPT 5.0 (<https://chatgpt.com/>) was opened and each cleansed scientific abstract was imported in, along with two separate commands, namely (i) (minimal prompts) - “rewrite this scientific abstract as a plain language summary for an 8th grade student in the US” Allow sequential simplification until a Flesch Reading Score of ≥ 60 has been obtained” and (ii) (extensive prompts) “Rewrite the following scientific abstract as a plain language summary for a young person aged 11 years old in the UK and include the following subheadings in the plain language summary: What was the purpose of the study? What did the researchers do? What were the findings of the study? What does this mean? Ensure that the plain language summary has a Flesch Reading Ease score of 60 or greater and make sentences



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short. Also please give the plain language summary a title. Try to make the plain language summary the same length as the original abstract.”

Determination of readability scores and text metrics

The readability of each source of information, namely the scientific abstract and the paired two AI-generated plain language summaries, was individually copied into the online subscription-based software, *Readable* (www.readable.com), which was used as guided by the manufacturer. All readability analyses were performed on text written in the English language. Readability values, including the Flesch Reading Ease, Flesch-Kincaid Grade Level, Gunning Fog Index and SMOG Index were calculated, as described previously.¹³ Two text metrics were also calculated, including words/sentence and syllables/word, as is generally the case with such studies. Readable.com was the software of choice as it has been used in several readability and recent studies within healthcare.¹⁴ McGrath and colleagues concluded that *Readable* was the best analytical tool to employ in readability studies, due to its user experience, capacity and accuracy.¹⁴

Statistical analyses

The readability data obtained underwent statistical analyses using GraphPad PRISM version 10.5.0 (774) (Boston, USA). To determine if the data followed a normal distribution, a normality test was performed on each set of data using the Shapiro-Wilk Test. Dependent on the normality of data distribution, for data that were normally distributed, one-way ANOVA (parametric) was performed to compare the means of normally distributed parameters. Data sets that were not normally distributed, the Friedman test (non-parametric) with multiple comparisons was performed. A p value of <0.05 (5%) was considered as statistically significant.

Results

Table 1 shows an example of the comparison of the narrative style and readability scores of an author-written Scientific Abstract, alongside artificial intelligence (AI) prepared Plain Language Summaries of the same Scientific Abstract, with two levels of input prompts, exemplified on the authors' own clinical paper published in the *Ulster Medical Journal* (Brennan OC, Moore JE, Millar BC. *Ulster Med J.* 2022; 91(1):9-18).¹⁵

Readability scores for the scientific abstracts of all 48 clinical papers for the Flesch Reading Ease score and the Flesch-Kincaid Grade Level are shown in Figure 1A and 1B. Mean values for the Flesch Reading Ease and Flesch Kincaid Grade Level of the scientific abstracts were 24.2 ± 14.1 (standard deviation) (Reference Target ≥ 60) and 14.4 (Reference Target ≤ 8), respectively, with mean words per sentence and syllables per word of 19.2 and 1.9, respectively. Descriptive statistics of the Gunning FOG and SMOG readability scores, as well as three other text metrics scores are shown in Table 2. The readability of AI-created plain language summaries

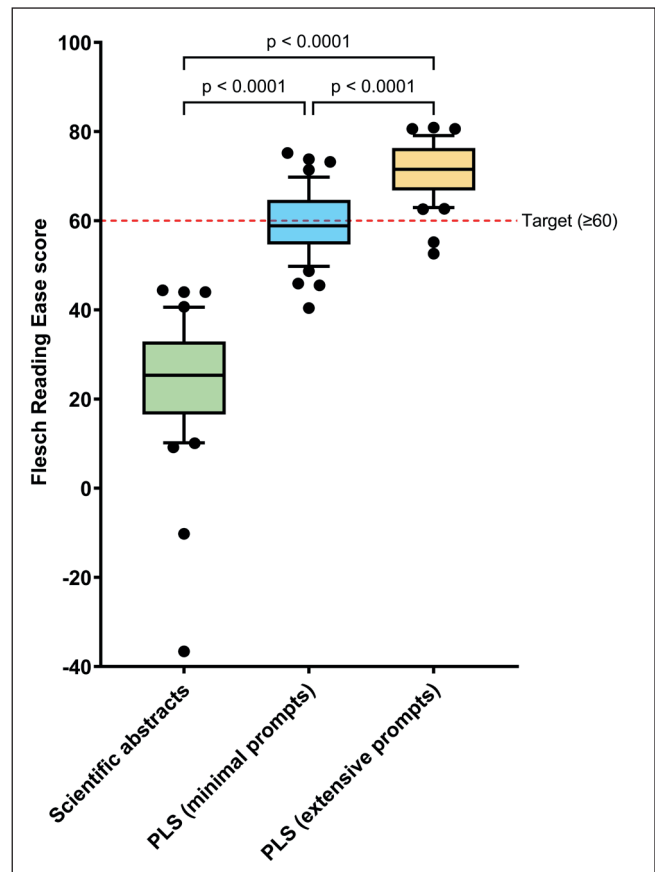


Figure 1A: Box and whiskers plot comparing the Flesch Reading Ease Score calculated from (i) UMJ Scientific Abstracts taken from Clinical Papers (n=48; 2020-2024); (ii) AI-generated Plain Language Summary of paired Scientific Abstracts (n=48) using minimal prompts and (iii) AI-generated Plain Language Summary of paired Scientific Abstracts (n=48) using extensive prompts.

Box represents 25th and 75th percentile and bar represents the median. Whiskers represent the 10th and 90th percentile and • represent outliers outside these percentile ranges. The dashed red line represents the target readability score. Statistical significance is shown, calculated using the Friedman test (non-parametric) with multiple comparisons performed. A p value of <0.05 (5%) was considered as statistically significant.

PLS = Plain Language Summaries

is also shown in Figures 1A and 1B. Figure 1C compares the words/sentence count in the scientific abstract, as well as in the Plain Language Summaries.

Discussion

In this study, we calculated the readability of all scientific abstracts published from original clinical papers over the last five years (2020-2024) in the *Ulster Medical Journal*. Having quantitatively established that these were outside the UK average reading age of 11 years, we employed AI-platforms to generate a lay/service user-friendly Plain Language Summary from the original Scientific Abstract. Through careful choice of input prompts, we were able to instruct the AI-platform to generate easy-to-read narratives,

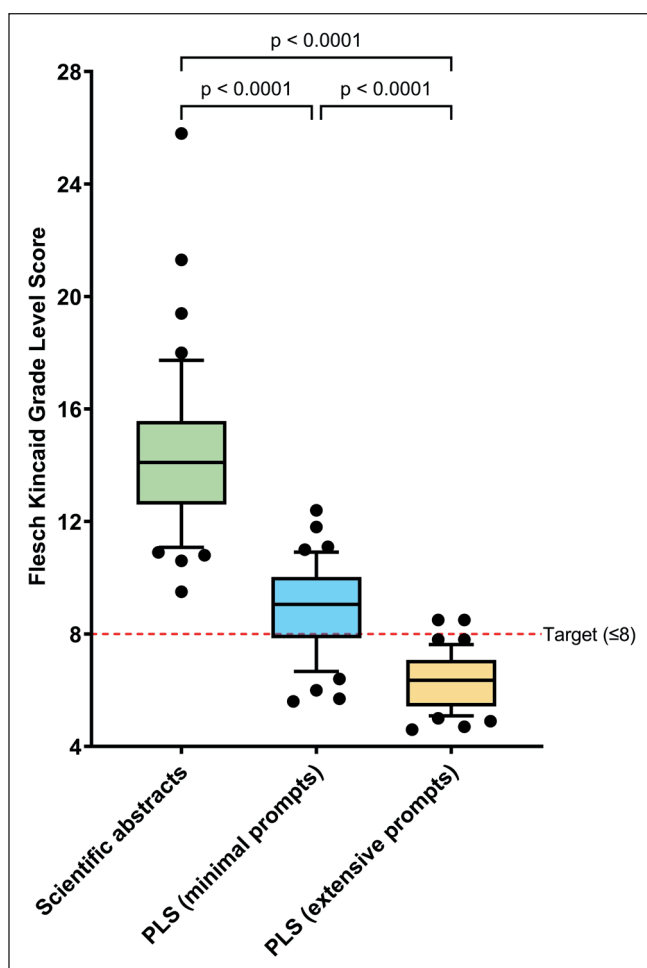


Figure 1B: Box and whiskers plot comparing the Flesch Kincaid Grade Level Score calculated from (i) UMJ Scientific Abstracts taken from Clinical Papers (n=48; 2020-2024); (ii) AI-generated Plain Language Summary of paired Scientific Abstracts (n=48) using minimal prompts and (iii) AI-generated Plain Language Summary of paired Scientific Abstracts (n=48) using extensive prompts.

Box represents 25th and 75th percentile and bar represents the median. Whiskers represent the 10th and 90th percentile and represent outliers outside these percentile ranges. The dashed red line represents the target readability score. Statistical significance is shown, calculated using the Friedman test (non-parametric) with multiple comparisons performed. A p value of <0.05 (5%) was considered as statistically significant.

PLS = Plain Language Summaries

aligning to readability reference targets. The ability to create fit-for-purpose Plain Language Summaries allows the lay public and service users to be become included in the family of readers of the journal.

On an average working day, the search engine, PubMed from the US National Library of Medicine estimates about 2.5 million users globally, generating around 3 million searches and 9 million page views.¹⁶ This is a free and reliable service cataloguing the scientific abstracts of scholarly works published by peer-reviewed journals globally. It is estimated that approximately one third of these users are

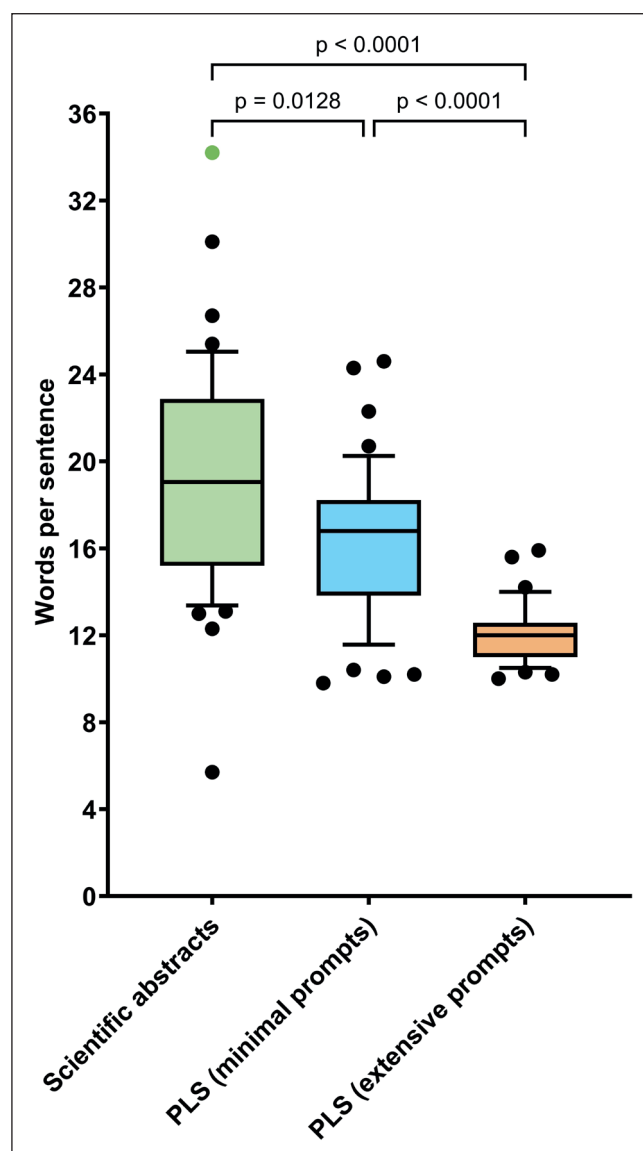


Figure 1C: B Box and whiskers plot comparing the words per sentence value, calculated from (i) UMJ Scientific Abstracts taken from Clinical Papers (n=48; 2020-2024); (ii) AI-generated Plain Language Summary of paired Scientific Abstracts (n=48) using minimal prompts and (iii) AI-generated Plain Language Summary of paired Scientific Abstracts (n=48) using extensive prompts.

Box represents 25th and 75th percentile and bar represents the median. Whiskers represent the 10th and 90th percentile and represent outliers outside these percentile ranges. The dashed red line represents the target readability score. Statistical significance is shown, calculated using the Friedman test (non-parametric) with multiple comparisons performed. A p value of <0.05 (5%) was considered as statistically significant.

PLS = Plain Language Summaries

not healthcare professionals, but rather lay members of the public attempting to access healthcare information from a respected and trusted source.¹⁷ These figures suggest that non-specialist users make up a significant minority of PubMed's daily audience.

Whilst scientific abstracts are not intended to be read by



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Table 1: Comparison of the readability of an author-written Scientific Abstract with artificial intelligence (AI) prepared Plain Language Summaries of the same Scientific Abstract

Scientific Abstract (written by authors)	Plain Language Summary of Scientific Abstract generated by AI (with minimal prompts)	Plain Language Summary of Scientific Abstract generated by AI (with extensive prompts)
<p>[Brennan OC, Moore JE, Millar BC. Ulster Med J. 2022; 91(1):9-18]</p> <p>Does social deprivation correlate with meningococcal MenACWY, Hib/MenC and 4CMenB/Meningococcal Group B vaccine uptake in Northern Ireland?</p> <p>Several meningococcal vaccines have been recently introduced into the infant and adolescent vaccination schedules in Northern Ireland to promote immunity to <i>Neisseria meningitidis</i>, protecting against meningococcal septicaemia and meningococcal meningitis. Maintained vaccination uptake is vital in securing individual protection as well as herd immunity. Several social factors have been described in influencing vaccine uptake and therefore it was the aim of this study to examine possible correlations between meningococcal vaccine uptake rates and indicators of social deprivation in Northern Ireland. Methods Vaccination data was retrieved from the Cover of Vaccination Evaluated Rapidly (COVER) database, for meningococcal vaccines (MenACWY, Hib/MenC & 4CMenB, as well as for MMR vaccine as a non-meningococcal control). Vaccine coverage data assessed included (i). Two doses of MenB by 12 months, (ii). All 3 doses of MenB by 24 months, (iii). Hib/MenC coverage, (iv). MenACWY (Year 12s, for NI) (v). First dose of MMR. Northern Ireland Multiple Deprivation Measures 2017 (NIMDM2017) were examined against 38 indicators in 7 domains. NI HSC vaccine uptake dataset for each vaccine was correlated with each indicator in the HSC T NIMDM2017 dataset. Regression analysis was performed to determine the relationship between vaccine uptake and deprivation indicators and coefficient of variation (R^2) was calculated for each of the indicators. R^2 values >0.7 were considered significant. Results For 4CMenB (all 3 doses by 24 Months), Hib/MenC, MenACWY and for MMR, correlation of variation (R^2) values > 0.7, were obtained for 17, 16, 0 and 17 social deprivation indicators, respectively. Significant deprivation indicators were (i) the proportion of 18-21 year olds, who have not enrolled in higher education courses at higher or further education establishments, (ii) the proportion of domestic dwellings that are unfit, (iii) the proportion of domestic dwellings with Local Area Problem Scores, (iv) rate of burglary, (v) rate of vehicle crime, (vi) rate of antisocial behaviour incidents (per 1,000 population), (vii) absenteeism at primary schools and (viii) the proportion of the population aged 65 and over living in households whose equivalised income is below 60% of the NI median. Conclusions Within the last two decades, incidence of meningococcal disease has been on the decline. The introduction of meningococcal vaccines has contributed to this decrease and uptake of such vaccines should remain a public health priority to maintain the decline in meningococcal disease. Identifying contributing factors to low vaccine uptake, such as, the association between local deprivation and uptake of meningococcal vaccines, should be of public health importance and acknowledged by local governments and policy makers in their efforts to enhance vaccine uptake, both infant and teenage vaccination. There is a clear correlation with educational deprivation measures such as absenteeism and poor educational attainment and reduced vaccine uptake, perhaps through lack of understanding and willingness to vaccinate. This is where the importance of a clear and coherent public health message surrounding meningococcal vaccination should be prioritised, particularly to establish innovative modalities in a multidisciplinary team approach, to reach out to and increase vaccine uptake rates in socially deprived communities in Northern Ireland.</p>	<p>Meningitis Vaccines – Why Some People Miss Out in Northern Ireland</p> <p>Meningococcal disease is a dangerous illness that can cause serious blood infections and meningitis (a swelling of the brain's lining). Several vaccines protect against it, and in Northern Ireland these vaccines are given to babies and teenagers. To keep people safe, lots of people need to get vaccinated this also helps protect people who can't get vaccines themselves (called herd immunity).</p> <p>Researchers wanted to see if there's a link between how often people get these vaccines and how poor or wealthy their communities are. They looked at data on four vaccines:</p> <p>MenB (2 or 3 doses depending on age)</p> <p>Hib/MenC</p> <p>MenACWY (for teenagers)</p> <p>MMR (measles, mumps, rubella used for comparison)</p> <p>They compared vaccine rates with 38 signs of social deprivation, such as low education, bad housing, high crime, and poverty among older adults.</p> <p>What they found:</p> <p>For babies' MenB and Hib/MenC vaccines, and for MMR, there were strong links between lower vaccine rates and things like:</p> <ul style="list-style-type: none"> Poor school attendance Low enrollment in college Poor housing conditions High crime rates Poverty in older adults <p>For the teen MenACWY vaccine, there was no strong link with deprivation.</p> <p>Why it matters:</p> <p>Meningococcal disease has become less common in the past 20 years, partly thanks to vaccines. But if poorer communities are less likely to get vaccinated, outbreaks could return. The study suggests that better public health communication especially in communities with lower education and higher poverty could help more people get these life-saving vaccines.</p>	<p>Do People in Poorer Areas Get Fewer Meningitis Vaccines in Northern Ireland?</p> <p>What was the purpose of the study?</p> <p>Meningitis is a serious illness that can make people very sick and even cause death. It is caused by a germ called <i>Neisseria meningitidis</i>. In Northern Ireland, new vaccines have been given to babies and teenagers to protect against this illness. Getting enough people vaccinated is important to keep everyone safe. The scientists wanted to see if people living in poorer areas were less likely to get these vaccines.</p> <p>What did the researchers do?</p> <p>The scientists looked at vaccine records for several meningitis vaccines. These included MenB, MenACWY, and Hib/MenC. They also checked the MMR vaccine as a comparison. They studied how many people got these vaccines in each area. Then they compared this to information about how poor or rich each area was. They looked at 38 different signs of poverty, such as how many people go to university, how many homes are in poor condition, and how many crimes happen. They then worked out if there was a strong link between poverty and vaccine rates.</p> <p>What were the findings of the study?</p> <p>They found that for MenB, Hib/MenC, and MMR vaccines, there was a strong link between vaccine rates and several signs of poverty. These included fewer young people going to higher education, more poor-quality homes, higher crime rates, more school absences, and more older people with low income. For the MenACWY vaccine, they did not find a strong link with these poverty signs.</p> <p>What does this mean?</p> <p>Fewer people in poorer areas are getting certain vaccines for meningitis. This might be because of less understanding about vaccines or not wanting them. To keep meningitis rates low, it is important for health services to focus on these areas. Clear and simple health messages, as well as new ways to reach people, could help make sure more children and teenagers get their vaccines.</p>

Table 2: Descriptive statistics of readability scores and text metrics relating to scientific abstracts and AI-generated plain language summaries.

	Gunning Fog score	SMOG score	Word count	Sentence count	Syllables per word
(A). Scientific Abstracts (written by authors)					
[Brennan OC, Moore JE, Millar BC. Ulster Med J. 2022; 91(1):9-18]					
Number of values	48.0	48.0	48.0	48.0	48.0
Minimum	9.3	10.4	72.0	4.0	1.7
25% Percentile	14.4	14.8	212.3	11.0	1.9
Median	16.5	15.5	266.5	14.5	1.9
75% Percentile	18.0	17.1	311.0	17.0	2.0
Maximum	25.6	23.8	581.0	66.0	2.5
Range	16.3	13.4	509.0	62.0	0.8
Mean	16.7	16.0	267.6	15.2	1.9
Std. Deviation	3.1	2.3	88.5	8.8	0.1
Std. Error of Mean	0.5	0.3	12.8	1.3	0.0
Lower 95% CI of mean	15.8	15.3	241.9	12.7	1.9
Upper 95% CI of mean	17.6	16.7	293.4	17.8	2.0
Coefficient of variation	18.75%	14.66%	33.08%	57.95%	7.645%
(B). Plain Language Summary of Scientific Abstracts generated by AI (with minimal prompts)					
Number of values	48.0	48.0	48.0	48.0	48.0
Minimum	7.0	8.3	89.0	4.0	1.4
25% Percentile	9.6	9.9	177.0	11.0	1.5
Median	10.3	10.8	205.0	12.5	1.5
75% Percentile	11.8	12.1	237.8	16.8	1.6
Maximum	14.1	13.6	306.0	21.0	1.7
Range	7.1	5.3	217.0	17.0	0.3
Mean	10.5	10.9	206.1	13.3	1.5
Std. Deviation	1.8	1.4	45.2	3.9	0.1
Std. Error of Mean	0.3	0.2	6.5	0.6	0.0
Lower 95% CI of mean	10.0	10.5	193.0	12.2	1.5
Upper 95% CI of mean	11.0	11.3	219.2	14.5	1.6
Coefficient of variation	17.29%	12.55%	21.92%	29.49%	5.482%
(C). Plain Language Summary of Scientific Abstracts generated by AI (with extensive prompts)					
Number of values	48.0	48.0	48.0	48.0	48.0
Minimum	5.1	5.8	175.0	16.0	1.3
25% Percentile	6.9	8.4	246.3	21.0	1.4
Median	8.0	8.8	278.5	23.0	1.4
75% Percentile	8.9	9.7	302.5	24.8	1.5
Maximum	10.3	11.3	372.0	31.0	1.7
Range	5.2	5.5	197.0	15.0	0.4
Mean	7.8	8.8	276.0	23.0	1.5
Std. Deviation	1.2	1.1	45.0	3.3	0.1
Std. Error of Mean	0.2	0.2	6.5	0.5	0.0
Lower 95% CI of mean	7.5	8.5	263.0	22.0	1.4
Upper 95% CI of mean	8.1	9.2	289.1	23.9	1.5
Coefficient of variation	14.93%	12.32%	16.30%	14.43%	5.751%



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the general public, there is therefore no formal requirement of authors of such works to moderate their language to attempt to include the lay audience. Therefore, most lay readers of scientific abstracts would find such abstracts to be difficult to read. Our study showed that the readability of scientific abstracts published in the last five years from original clinical papers published in the *Ulster Medical Journal* is poor, where the readability of scientific abstracts published ranged from -36.6 to 44.4, as determined by the Flesch Reading Ease score, thereby exceeding the average 11 year old reading age of someone in the UK. In the UK, Health Education England (HEE) recommends that patient resources be written at a level suitable for comprehension by an average 11-year-old.^{18,19}

None of the scientific abstracts meet the readability reference targets. When we used minimal instructions for the AI platform, approximately only half of the plain language summaries now met the reference target. However, previous evidence-based guidance from Zarshenas and colleagues,²⁰ as well as by Stoll and colleagues²¹ have indicated important prompts to include to produce a quality plain language summary. Adopting this guidance, we developed an extensive prompt, to be fed into the AI platform along with the authors' scientific abstract, which when applied, drove readability to within reference targets for 46/48 (96%) scientific abstracts.

AI-generated Plain Language Summaries were created in this study using ChatGPT 5.0, employing a standard PC computer with access to the internet. No specialised training was necessary to use this AI platform, apart from following given prompts and instructions from the AI-platform.

Study limitations

In this study, we examined papers from a single journal source, in order to ensure that all papers were written using a standardised set of "Instructions to Authors" guidelines, prior to the application of AI tools and thus attempting to avoid bias due to variations in style. Future studies may wish to compare AI narratives from several journals with differing "Instructions to Authors" guidelines, to establish how robust AI-generated narratives are from sources with differing styles and formats.

Readability describes how easily a piece of text can be read without difficulty by the target audience. Readability considers numerous factors including the complexity of the literature, familiarity with the topic, typography and legibility. Therefore, readability is a crucial component when service users read medical information relating to their diagnosis, management and treatment. However, readability does not calculate or assure any level of understanding. For example, if a piece of text narrative has a good readability score, the reader could still find it challenging to understand the topic being discussed.

Additionally, this study recognises that it did not attempt to check the accuracy or completeness of the AI-generated

narratives, due to the fact that the authors were not specialists in the topics described in the 48 abstracts, so could not authoritatively comment on these aspects of AI-created materials. However, to control this aspect, we strongly advocate that all Plain Language Summaries generated by AI are thoroughly checked by the original authors, particularly for accuracy and completeness, during the proofing stage, prior to publication and subsequent release to the service user community. Moving forward, we believe that further studies could now be undertaken along with service users in a co-design and co-production manner, to help build upon the objective nature of the current study, and help inform patient and service user acceptability of AI.

Proposed adoption of AI-generated Plain Language Summaries

Plain language summaries are becoming more frequently employed by editors of medical journals, although they remain in a minority. A recent study by Gainey and colleagues found that of 534 journals across 10 non-communicable disease areas and 11 journal categories, only 27 (5.1%) contained text-based instructions for Plain Language Summaries.²² These authors showed that there was much heterogeneity and inconsistency in guidance given for the writing of plain language summaries. Further related work by Pal and colleagues showed that minimising variability of the Plain Language Summary may help greater adoption and impact of these resources.²³ Most recently (June 2025), in a seminal paper by Edwards published in *Medical Writing*, the findings of a collaboration between experts from over 15 US and EU organisations, including industry, academia, and a patient-focused nonprofit, were discussed, which detailed how AI can be responsibly applied to Plain Language Summaries.²⁴ These included (i) prompt engineering considerations, (ii) considerations for AI governance, (iii) considerations for AI disclosure, (iv) examples of advanced AI architecture for Lay Summary creation and (v) helpful tools and resources.²⁴ These findings by Edwards will help to enhance the current practice of adopting and employing Plain Language Summaries to support patient health literacy.

When the editor and editorial board of a medical journal commit to the inclusion of Plain Language Summaries, the delivery of PLS may follow two routes, namely (a) that the PLS is prepared and submitted by the authors of the original work or (b) the journal prepares a PLS from the authors' submitted scientific abstract using AI-platforms, using extensive prompts. This draft AI-generated PLS is sent to the authors as part of the peer-review process, for checking and proofing, particularly relating to accuracy and completeness. Both the Scientific Abstract and the Plain Language Summary are subsequently published side-by-side with the original work in the journal.

Conclusions

Medical journals may reach out to lay readers, including

service users, patients, family and friends, through new innovation with the inclusion of a Plain Language Summary. Scientific abstracts are written at a level which is beyond the average reading age of 11 years old in the UK. Employment of AI platforms may generate narrative text which can be successfully tailored for specific reading ages, with optimal readability. Effective communication of medical research findings from medical and scientific papers is vital for service users to enhance their health literacy, thereby helping promote better clinical outcomes, as well as promoting inclusivity for lay readers.

DISCLOSURES & STATEMENTS

Ethics Statement

This study did not involve human or animal subjects. All of the material used in this study was openly and freely available to the public and within the public domain.

Patient consent for publication

Not applicable.

Transparency declarations/Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial, financial or other relationships that could be construed as a potential conflict of interest.

Specific author contributions:

CRedit authorship contribution statement:

John E Moore: Conceptualization; Formal analysis; Methodology; Roles/Writing - original draft; Writing - review & editing.

Beverley C. Millar: Conceptualization; Formal analysis; Methodology; Writing - review & editing.

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Availability of Data and Materials

All data supporting the findings of this report are freely available in the public domain for access by readers.

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Eliminating a disease

Royal Victoria Hospital Annual Oration, 4th October 2024

Dr Neil McDougall*

The Orator has traditionally had two main tasks. Firstly, to welcome all our medical students, especially those commencing third year. On behalf of the Royal staff you are most welcome and I hope you will enjoy your clinical attachments. My Oration is primarily directed to you and to those in the early stages of their careers although hopefully there is something here for all of us.

My second task of delivering a thought-provoking Oration is somewhat more challenging. I had the privilege of working under Dr Norman Campbell and I love the humorous opening remarks from his oration in 2005 when he said that the Orator has the opportunity of 'airing views on some topic of interest to himself if not to anyone else'¹. My subject is definitely close to my own heart and I hope that my remarks will be of at least passing interest to others.

Can a disease be eliminated?

My interest in hepatitis C is well known. The trajectory of this disease mirrors my own career – it was first identified in 1989², the year I graduated from Queens. As you will hear it may be eliminated before 2030 by which time I expect to be retired - but hopefully not eliminated. My title is derived from phase one of the WHO Global Health Strategy to eliminate viral hepatitis as a major public health threat by 2030³. It was published in 2016 and the UK signed up the same year. I want to consider the lessons we can learn from the hepatitis C story and through this to consider what it really means to 'eliminate a disease'.

WHO had good reason for committing to an elimination strategy for viral hepatitis. In 2015, viral hepatitis was the only major infectious disease with a rising global death rate, overtaking HIV and tuberculosis (Figure 1). This was prior to Covid-19 which I will mention later. The strategy applied to the whole hepatitis alphabet – A, B, C, D and E - but the emphasis was on hepatitis B and C which at that time accounted for 95% of the estimated 1.4 million deaths from viral hepatitis each year.

Several circumstances in 2015 suggested the time might be right for elimination. Vaccines for A and B were well established and work was evolving on hepatitis E vaccination. Strategies were in place for prevention of mother to baby transmission of hepatitis B, reductions in healthcare transmission of hepatitis B and C and harm reduction for people who inject drugs. Most importantly, new potent anti-

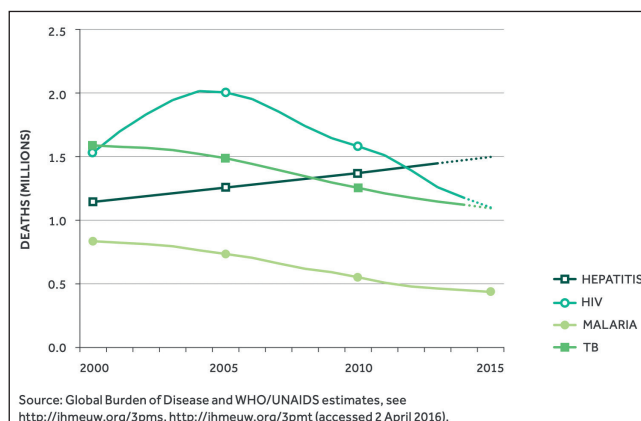


Figure 1. Estimated global number of deaths due to viral hepatitis, HIV, malaria and TB, 2000-2015

viral drugs for hepatitis C had just been released. You could not fault the WHO for being optimistic.

Of course, the WHO had an excellent track record in this respect, having eradicated smallpox⁴. For the pedants among you, there is a difference between elimination and eradication. Elimination means reducing the incidence of an infection to zero but requires ongoing interventions for control. Eradication means a permanent reduction to zero with no need for ongoing control.

Like so many infectious diseases, smallpox is known to have existed in ancient Egypt some 3000 years ago. More recent records from the past few centuries show that smallpox had a devastating mortality rate of up to 30% and it is thought to have killed 300 MILLION people in the 20th century alone.

Many of you will know the story of Dr Edward Jenner who noted the protection or immunity to smallpox that milkmaids developed due to their exposure to cowpox which was obviously a much less dangerous but related virus. This led Jenner to develop the first vaccine against variola in 1796⁵.

It took over 150 years but WHO launched an eradication program in 1959. A lesson we must all remember is that despite having an excellent vaccine, the program failed – it was ineffective due to lack of funding and commitment. A

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well-resourced intensified relaunch in 1967 proved much more successful. The last case in Africa occurred in 1977 and by 1980 WHO declared smallpox eradicated – famously the only infectious disease ever to have been eradicated.

Two cautionary tales are worth noting. Monkeypox or Mpox as it is now known, is from the same orthopoxvirus family as smallpox although thankfully it is much less infectious and less virulent. You may be aware that there was a surge in cases in the UK in 2022. It is thought that the recent resurgence of cases of Mpox worldwide is in part due to the loss of immunity to smallpox. Secondly, the variola virus still exists in two laboratories for research purposes – the CDC in Atlanta Georgia and the VECTOR institute in Russia. I will let you decide whether that makes you feel safer or not.

I must tell you a little bit about the nature of the hepatitis C virus so that you can better understand what follows. HCV is a blood borne virus that damages the liver. The epidemic of hepatitis C in the 20th century has been fuelled by new parenteral routes for blood-to-blood transmission: immunisations, medical treatments, blood transfusions and of course injecting drug misuse which began just over 100 years ago.

Most people are unaware that they have been infected because less than 20% become jaundiced. Yet over 80% of infected individuals fail to clear the virus and develop chronic hepatitis C which over a period of many years can lead on to cirrhosis. After 20 years, 20% of people infected with hepatitis C will have cirrhosis with its serious life-threatening consequences (Figure 2). Therefore, you can see the value in seeking to eliminate such a silent killer.

This quote from Donald Rumsfeld always makes me smile. In 2002, less than 6 months after the horrific 9/11 terrorist attack on America, he said the following in a news conference at the U.S. Department of Defence:

‘... as we know, there are known knowns; there are things we know we know. We also know there are known unknowns; that is to say we know there are some things we do not know. But there are also unknown unknowns—the ones we don’t know we don’t know.’

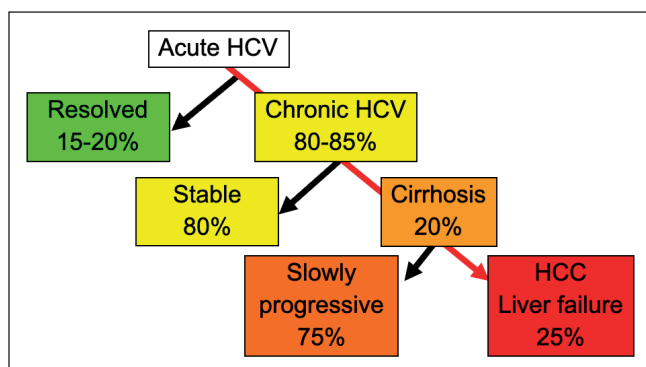


Figure 2. Outcome after acute hepatitis C virus (HCV) infection

The comments led to widespread amusement, ridicule and parody but he was using a well-recognised term, if a little clumsily. Unknown unknowns refer to risks that we don’t know about. We now understand the relevance of this statement to counter terrorism but it applies equally to many other areas and especially to medicine. Hopefully you will soon see the relevance to hepatitis C.

Medical students probably grow tired of being told that in 10 years 90% of what you have been taught will be wrong. But it is remarkable how quickly things change in medicine. The most obvious recent example of this is Covid-19. Until December 2019 there was no knowledge or teaching relating to the nature of this devastating infection. This was truly an ‘unknown unknown’. Yet within 4 months doctors were exchanging emails and WhatsApp’s to learn from other countries about the clinical features and tips for treatment. Our intensive care colleagues learned on the job that nursing patients in the prone position gave a better outcome. Radiologists learned the telltale signs of Covid-19 on CT imaging and physicians noted the quirky changes it caused in routine blood tests. Four years later we have thankfully moved on to a situation where our lives have been transformed by a vaccination program and we rarely have Covid-19 cases in our ICUs. Students and young doctors, you will face massive new challenges that we cannot teach you about – but you should be encouraged by the clear evidence from Covid-19 that the basic training you have received prepares you for these unknown unknowns.

Within hepatology we have not had anything as seismic or newsworthy as Covid-19, but the transformation of hepatitis C across my career has been remarkable – from an unknown condition to one on the verge of elimination. As students we were taught nothing of hepatitis C because it was not identified before I graduated. However, it seems clear that it was not truly unknown prior to 1989. The shadows and footprints of hepatitis C were already very evident for at least a few decades.

I believe I am required to have at least one piece of fine art in



Figure 3. The Siege of Acre in 1799, engraving/print attributed to Francois-Rene Moreaux

my Oration and I do not want to disappoint my colleagues. Epidemics are the rapid spread of a disease to a large number of people within a short period. There are reports of epidemics of jaundice or hepatitis from as far back as China 5000 years ago although early accounts were confused with other illnesses such as malaria. Hippocrates was the first to clearly describe clinical features of epidemic jaundice⁶. The existence of epidemic hepatitis has been more clearly documented in military campaigns since the 18th century. Defence of the breach at St Jean d'Acre (Figure 3) portrays one of the earliest such examples from the unsuccessful siege by Napoleon of the walled city of Acre. These epidemics seem fairly clearly related to hepatitis A which is transmitted by the faecal-oral route and likely to flourish in battlefield conditions with poor sanitation.

But we are not interested in epidemics as that is not the route of transmission for hepatitis C which is blood borne. Serum or post-transfusion hepatitis was suspected for a few centuries but became well established during the second world war. In 1942 there was a major outbreak of hepatitis in the US Navy related to contaminated yellow fever vaccine⁷. This was one of the earliest clear examples of injections causing hepatitis infection. From the late 1940s it was known that transfusions carried a risk of post transfusion hepatitis and cautions were issued by many including WHO in 1952 who stated that the risk could be reduced by preventative measures. In 1965 there was the landmark discovery of hepatitis B – a virus transmitted through both blood and also bodily fluids such as semen⁸. Hepatitis B turned out to be the cause of the yellow fever outbreak from contaminated vaccine in 1942. Its discovery led to screening of all blood products in UK by 1972. As a consequence it became clear that patients could acquire a post-transfusion hepatitis from hepatitis B negative blood products – non-A non-B hepatitis. The existence of a non-A, non-B post transfusion hepatitis was confirmed and published in the Lancet in 1974⁹ – we now know the vast majority of such cases were due to hepatitis C. Opportunities to reduce transmission were missed for almost 20 years until 1991 when screening of all blood donations for hepatitis C began (2 years after discovery of hepatitis C)¹⁰.

I do not think hepatitis C was an unknown unknown when I was at medical school, more like a known unknown. We knew there was something there. But it was unnamed, had no treatment, no prognosis and no diagnostic test prior to 1989. Those of you at medical school will undoubtedly encounter diseases that were never named while you were at university. In hepatology we now use the term non-ABC hepatitis for acute hepatitis illnesses with no serological diagnosis. The RVH Liver Unit admits several such cases every year. Perhaps in 20 years or less someone in the audience will be standing here giving it a proper name (and hopefully describing a cure).

The Infected Blood Inquiry

I want to move on to the difficult subject of NHS Inquiries.

I know that both those in healthcare and members of the public have been deeply scarred by the findings of inquiries that are very fresh in the memory or indeed ongoing. Inquiry reports are invariably critical. Justice O'Hara who led the hyponatraemia inquiry summarised it well when he said:

*'It is the task of an Inquiry to focus specifically on what has gone wrong, not on what has gone right and such close focus can act as a distorting lens'*¹¹.

Although we may feel aggrieved by critical conclusions, we need to appreciate that all such inquiries have their origins in patients, relatives or the general public feeling an enormous amount of pain, anger and confusion, and sometimes a need to have someone to blame. We must pause to study these inquiries and learn from them. With that in mind, let us consider The Infected Blood Inquiry which published its report just a few months ago in May 2024¹⁰. It is a crucial part of the hepatitis C story.

The Inquiry was set up to investigate what Lord Winston described as the 'worst treatment disaster in the history of the NHS'. Patients received contaminated blood or blood products mostly during the 1970s and 1980s with catastrophic effect. The contaminated blood transmitted HIV, Hepatitis C and to a lesser extent hepatitis B and D. Two main groups were impacted:

- those with bleeding disorders of whom over 6000 were infected with Hepatitis C
- the general population who were given blood for a variety of reasons, causing almost 27000 to be infected with hepatitis C

It led to more than 3000 deaths and you may wonder how this could have happened. A simple (but inadequate) explanation might be that screening of blood for these infections was not possible. Screening of blood donors for hepatitis C was not introduced in UK until 1991. But there were other factors. A key issue was that the UK was not self-sufficient for blood products and had to import from USA. It was well known that USA used paid donations from high-risk donors (prison populations, iv drug users) and there were widespread recommendations about not using such sources¹⁰. As far back as 1952 the WHO stated that the risk of serum hepatitis could be reduced by preventative measures such as donor selection. This was clearly at odds with the policy to use US derived products.

Secondly, there was complacency regarding the risk of non-A, non-B hepatitis. Patients and the public were incorrectly reassured including parliamentary statements despite clear evidence of progressive liver damage from 1980¹².

Lastly, it is clear that those of us who have been involved in the progressively successful treatment program since the early 2000s are not blameless. We failed to fully comprehend the emotional and psychological trauma caused to patients and families by contaminated blood related infections



many years previously. The Infected Blood Inquiry report is an extremely challenging read but I would commend it to everyone present today – the summary is only 6 pages long and I guarantee it will impact and improve your clinical practice.

The Stigma of Hepatitis C

There is a striking contrast between the two main cohorts of patients affected by HCV. In our earliest data for Northern Ireland from the 1990s, we found that roughly half of HCV patients acquired the infection through intravenous drug use or IVDU (Figure 4)¹³. The majority of the rest came from the group infected through contaminated blood products. Moving forward 25 years over 95% of newly detected cases

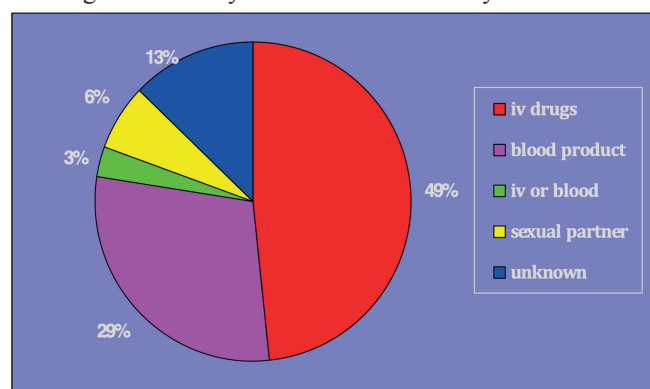


Figure 4. Mode of transmission of hepatitis C in Northern Ireland from 1992-1997

have intravenous drug use as their main risk factor. Hepatitis C is now inextricably linked with IVDU. You will appreciate that this is a source of great distress for those infected through contaminated blood – to be repeatedly asked if they used IV drugs in the past. Remarkably, I have found over the years that many of our IVDU patients consider hepatitis C to be much more of a stigma than their IV drug use. Patients refer to being ‘dirty’ and this can actually be a motivating factor for chaotic patients to complete HCV treatment. Of course stigma is nothing new in liver disease and the greatest stigma of all for liver patients is alcohol. There is some good reason for being fearful of the label. Thirty years ago a diagnosis of alcohol related liver disease could prevent you from getting an ICU bed. Thankfully those days are long gone. I have deviated from my subject but I hope you will consider this curiosity of why we/the public stigmatise some liver diseases, like hepatitis C, and yet not other lifestyle associated conditions such as cardiovascular disease. We have considered the history of hepatitis C and those most likely to be affected. Now we must turn our attention to how such a disease might be eliminated.

Preventing Hepatitis C

Prevention is better than cure and where better to start than with vaccination, the key contributor to the eradication of smallpox. Alas due to the nature of HCV with its many subtypes and hypervariable regions, very little progress has

been made on an effective vaccine. Even the antibodies generated by an infection fail to protect patients from reinfection after successful viral clearance.

The holy grail in preventing HCV transmission in the modern world is to eliminate the scourge of intravenous drug use. Yet events continually conspire against us. Even Covid-19 inadvertently increased the transmission of HCV. Heroin supply chains to Northern Ireland were interrupted and as a consequence intravenous drug usage switched to cocaine which requires multiple injections per day compared to heroin. Multiple opportunities for infection. I am always impressed by the amazing work carried out by our drugs and addictions teams and health inclusion teams across the Province but our data suggests that at best we are in a stalemate and certainly not winning. Unless we overcome the scourge of IVDU, hepatitis C will not be truly eliminated.

If we cannot prevent hepatitis C infections, then what about removing the infected organ. The principle around organ transplantation is to remove a diseased organ and replace it with a healthy one. This is not a practical solution but we must consider it because at one time hepatitis C had a major impact on transplantation. It also allows me to tell you a success story.

Figure 5 shows liver transplant numbers for Northern Ireland over 30 years up to 2020. The first liver transplant for a Northern Irish patient took place in Addenbrookes in 1988, just before the start of this chart. Virtually all our liver transplants are now done in King’s College Hospital, London. Numbers were small in the next few years but access to Liver Transplant services were transformed in September 2000 when Dr Michael Callender and Prof John O’Grady from King’s established a satellite clinic in Belfast. The purpose was to optimise care for liver transplant

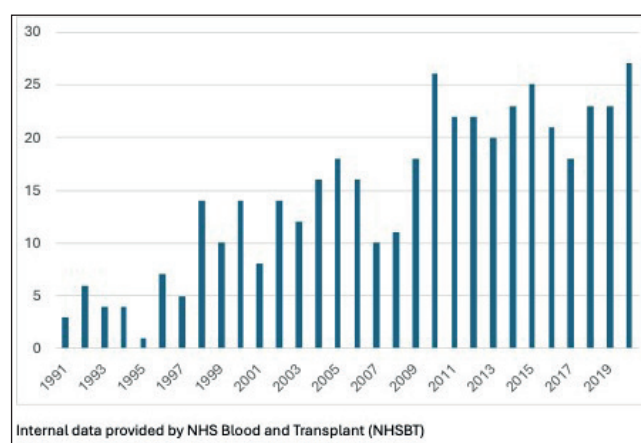


Figure 5. Distribution of 441 first time liver transplants carried out on patients from Northern Ireland in King’s College Hospital, London from 1991 to 2020

recipients and improve access to transplantation. You can see the impressive rise in numbers over the next 20 years.

Figure 6 shows the success of the transplant program in NI

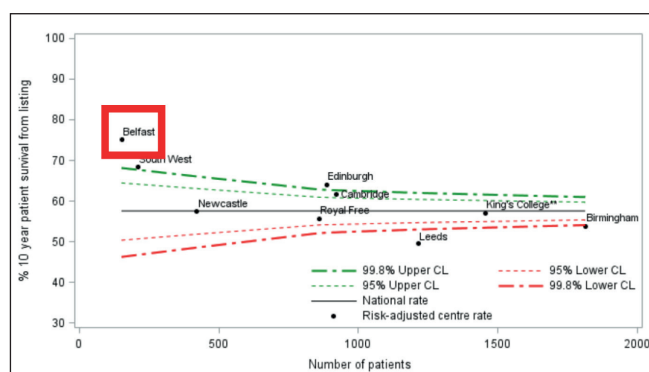


Figure 6. Risk adjusted 10 year patient survival rate from time of listing for adult elective first liver only registrations in UK from 1 Jan 2004 to 31 Dec 2015

over 30 years up to 2020¹⁴. Our number of transplants per 100,000 more than trebled over three decades. Previously our transplant rate was only half the rate for the rest of UK but in the past decade we have been slightly better off than the rest. This expansion in transplant numbers was accompanied by excellent survival figures (Table 1). Although our numbers are smaller, the Regional Liver Unit outperformed every other UK transplant centre in 10-year survival figures. Surely such a successful transplant program would provide some answers for hepatitis C?

Decade	Northern Ireland transplants/100,000	Rest of UK transplants/100,000
1991 - 2000	0.3	0.59
2001 - 2010	0.53	0.70
2011 - 2020	0.99	0.96

Table 1. Number of liver transplants per 100,000 population for Northern Ireland and rest of UK over a 30 year period from 1991-2020

By 2004, hepatitis C had become the leading indication for liver transplantation across the UK due to failing cirrhotic livers and drug therapies with a high failure rate¹⁵. Projections at that time suggested that by 2020 hepatitis C would account for all available organs for transplantation. Worse still, transplantation did not deliver a good outcome. Recurrent disease in the new liver was the norm, causing rapid progressive damage that was much more aggressive than the original illness. Re-transplantation was often required within 2-3 years. These outcomes have been transformed by modern drug therapies. Contrary to projections in 2004, today in Northern Ireland transplantation is rarely needed for advanced liver disease due to hepatitis C.

Treating hepatitis C

If prevention and transplantation are impractical or impossible solutions, then we must look to curative drug therapies. Figure 7 shows a summary of the amazing progress in drug therapy for hepatitis C genotype 1 (the most common sub

type of HCV in UK) over 30 years. The goal of treatment was to achieve long term clearance of the virus also known as a sustained virological response or SVR, meaning that the virus stays away permanently after treatment stops. You could call it a cure if you did not have cirrhosis.

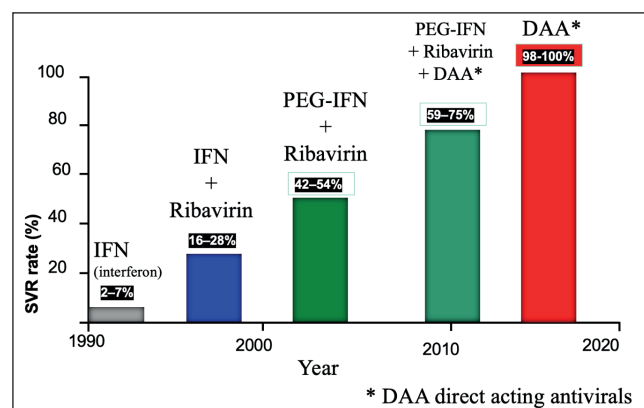


Figure 7. Evolution of drug therapy for hepatitis C genotype 1 in achieving a sustained virological response (SVR)

Interferon monotherapy was actually used for non-A, non-B hepatitis in the late 1980's before hepatitis C was identified and had been shown to cause some normalisation of LFTs. It became clear that hepatitis C usually relapsed after finishing treatment. The side effects of this subcutaneous injection 3 times per week were quite debilitating, and treatment lasted 6 to 12 months. Worst of all, the SVR was in single figures.

The situation improved in the late 1990s with the addition Ribavirin, an oral antiviral tablet, and there was a substantial step forward in 2002 with the approval of a new once weekly Pegylated Interferon injection alongside daily ribavirin tablets – SVR improved to around 50%. Further increments in SVR occurred with the development of Direct Acting Antiviral tablets or DAAs which were introduced to Northern Ireland in 2011. Nevertheless up until 2015 all treatment was still based around interferon injections with all its associated issues. The dramatic breakthrough came with the release of Sofosbuvir in 2014, a DAA which became the cornerstone of combination tablet-based therapy¹⁶. By 2017, we had established treatment for hepatitis C with once daily tablets for 8-12 weeks, minimal side effects and a cure rate of 98% for all. Surely the advent of such potent and safe drug therapies would spell the end for hepatitis C.

It is important to note that the NI commissioners have worked closely with the Regional Liver Unit over the past 15 years to ensure that patients in NI have been given immediate access to the best available treatments for hepatitis C as soon as NICE approves them. They have been one part of a very large team seeking to deliver hepatitis C elimination. In the early 2000's we realised that hepatitis C patients preferred to engage with our nurse specialists rather than with doctors in a clinic. Our two nurse specialists Karen Patterson and Isabel Stewart helped many patients through difficult times with interferon-based treatments. In more recent years, nurse specialist Orla McCormick has led all patient interface on



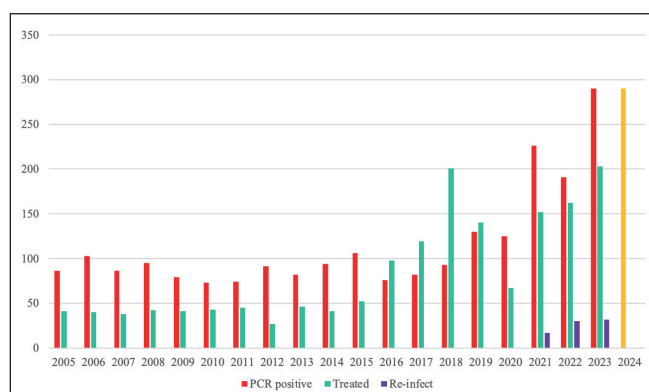


Figure 8. Number of new hepatitis C cases detected and treated in Northern Ireland

RVH site and liaison with our treatment partners particularly in NI prison service and addictions services. Prison outreach clinics began in 2017 and the frontline of HCV elimination is now in prison healthcare, drugs and addiction units, health inclusion and homeless services all of whom are delivering treatment to patients. The importance of a team-based approach to HCV elimination was made clear by the Department of Health in the Northern Ireland Elimination Strategy, launched in 2021¹⁷. Without this multi-faceted and multidisciplinary team, a conventional consultant led hospital-based clinic would fail to reach more than 10% of those we currently treat.

Figure 8 shows the scale of the problem. The number of hepatitis C cases detected in the province each year since 2005 is shown in red (with an estimate for 2024 in yellow) and the number of cases started on treatment each year shown in green. In the decade prior to the launch of tablet-based treatment, only half of those detected actually came through to have treatment. This was partly due to the side effect profile of interferon-based treatment but also due to the chaotic nature of IVDU patients and their inability to engage with conventional services. There was a surge in treatment from 2016 to 2018 due to the introduction of the highly effective tablet based Direct Acting Antiviral (DAA) therapy but then things changed. It became clear that the Regional Liver Unit had exhausted the supply of patients willing to engage with conventional services in a hospital for treatment. The networks became our crucial link to deliver treatment closer to where patients were.

Thankfully, elimination strategies have at last shone a light on the fact that the greater burden of hepatitis C infection is carried by marginalized and vulnerable populations - people who use drugs, those who are incarcerated and the homeless. It is a harsh reality that in our society there is a terrible overlap with these 3 problems. I know that a few of those present today have provided healthcare services within prison. For those of you who have not, experiencing our prisons first hand makes a lasting impression. I am sure you are all familiar with the quote from Dostoevsky that:

'a society should be judged not by how it treats its outstanding citizens but by how it treats its criminals'.

Perhaps you noticed the recent media outcry about a prisoner release program to create capacity in UK prisons. The thing that caught my eye was Charitable Organisations highlighting that the policy simply resulted in more released prisoners becoming homeless due to flooding the system. Our internal audit data several years ago demonstrated that we lose touch with 90% of prisoners with hepatitis C on their release from prison. To date, we have struggled to resolve the issue of treating the marginalised and vulnerable patients who get hepatitis C, and we as a society must do better.

Before leaving the data in Figure 8, I must explain the upturn in hepatitis C cases in 2021, ironically the same year that we released the Northern Ireland Hepatitis C Elimination Plan. There are two main factors driving the upturn. Firstly, intravenous drug use. I have already mentioned the changes Covid-19 caused in the IVDU community with respect to choice of drug and frequency of injection. In addition, we are now seeing more cases of intravenous drug users re-infecting – see the purple bars in figure 8. A decade ago this was very uncommon but now we are seeing 20-30 cases per year. Even our outreach services are now telling us that they have reached the point our clinics reached several years ago, where they have treated most of the patients who are willing to have treatment. At last count we had over 400 patients on our Liver Unit database with HCV who have declined to attend for treatment.

The second reason for an increase in cases is better detection. Hepatitis C became a notifiable disease in 2021 which has helped. However prior to 2021 we had excellent data on annual HCV incidence through the Regional Virus Laboratory. The more important factor is that our Network and Elimination Strategy has improved detection through more point of care testing in outreach services, especially the prison service. The size of the challenge ahead has become so much clearer, and it is growing!

Conclusion

What do we mean by 'Eliminating a Disease'? The WHO has been very clever in defining 'Elimination'. The goal is to eliminate hepatitis C as a public health threat, not to eliminate it completely as was done with smallpox. The overriding targets were to reduce incidence, reduce mortality and seek to treat 80% of those infected³. Perhaps these targets are an acknowledgement that treating everyone with HCV is not possible or practical.

These targets have been updated and whilst we already easily meet the mortality target in Northern Ireland, our current annual incidence (15 per 100,000 population) is more than double the 2030 target. I am confident that we will meet the target to Eliminate Hepatitis C by 2030 using the WHO definitions but we can and should do so much more. Elimination means more than just meeting target numbers.

I have described 4 things that are needed to eliminate hepatitis C:

- i. You need to know the disease. It seems clear that it took us far too long to understand hepatitis C and as the infected blood inquiry showed, much harm was done when warnings of a blood borne hepatitis were not heeded.
 - ii. You must have a good treatment and thankfully after 25 years a tablet with a close to 100% cure rate is readily available. If I was to nitpick I would say that 8-12 weeks for a treatment course is far too long for the type of patient we need to treat.
 - iii. And most importantly, you need to know your patients and understand the impact of their disease and the barriers to their successful treatment. Hepatitis C has impacted on two very disparate groups
 - those infected by contaminated blood and their families all of whom will take decades to move on from their trauma, if ever
 - and those who seemingly cannot help but infect themselves through iv drug use.
- Neither of these issues will be eliminated by 2030 but at least they are being addressed.
- iv. When you understand the disease, the treatment, and the patients' issues, you then need an enormous multifaceted integrated team and the resources to enable that team to deliver the cure. That is what it took to eradicate smallpox and nothing less will work for the true elimination of hepatitis C.

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Medical History

The Development of Neonatal Intensive Care in Belfast, Northern Ireland

Mark McC Reid¹, Thomas F Baskett²

Just over one hundred years ago the Edinburgh obstetrician, John William Ballantyne (1861-1923), was among the first to anticipate the need for specialist neonatologists¹.

“There is a need for specialists in neonatal medicine. This applies to doctors and nurses as well as teaching and construction of hospitals. The specialist in neonatal diseases and the nurse intensively trained and expert in the management of delicate newborns will be commonplace ere long”.

Until the twentieth century the care and resuscitation of the newborn, if needed, was provided by the accoucheur – midwife or physician. There are references to newborn resuscitation in biblical times, including mouth-to-mouth respiration by Elisha in the Book of Kings². Indeed, basic resuscitation of the newborn has probably been carried out for millennia as midwives instinctively tried to revive weak and depressed infants at birth. In the eighteenth century two British obstetricians, William Smellie (1697-1763) and Benjamin Pugh (1715-1798), used ‘air pipes’ inserted into the mouth and trachea to initiate early respiration in depressed neonates^{3,4}. Pugh also gave a remarkable description of neonatal mouth-to-mouth respiration that has not been improved upon in the intervening 270 years:

*“If the child does not breathe immediately upon delivery wipe its mouth, and press your mouth to the child’s, at the same time pinching the nose with your thumb and finger, to prevent air escaping; inflate the lungs, rubbing it before the fire: by which method I have saved many”.*⁴

The benefit of incubators to provide warmth for the neonate followed the observation of the incubation of eggs in nature and in poultry farming. The obstetrician Etienne Tarnier (1828-1897), used heated incubators for premature newborns, after observing their use for hatching the eggs of exotic birds in the Paris Zoo. Incubators were first developed in the mid to late nineteenth century in Russia, France and Germany, and were established in premature baby units in the eastern United States by the early twentieth century⁵. By the 1950s there was proof from a randomised controlled trial that warming premature infants improved survival⁶.

Incubators arrived in Belfast in 1959, providing both warmth and a consistent oxygen supply. They reduced the risk of hypothermia, which was a common damaging factor during the transfer of infants from the labour ward to the nursery.

To a degree they also reduced handling of the infant and provided isolation and protection from infection.

While the general importance of nutrition was recognised, the risks of aspiration and poor motility of the premature infant’s bowel led to the belief, particularly in the United States in the 1950s, that the premature infant could be safely starved for the first few days after birth. This was not followed in Belfast where early gavage feeding was adopted. Initially this was via soft rubber catheters, to be supplanted by less irritant polyvinyl feeding tubes in the late-1940s. Early feeding reduced the risks of hypoglycaemia and jaundice. ‘Formula’ feeds were developed with varying proportions of protein, fat, carbohydrate and other nutrients.

Special Care Baby Units

By the early twentieth century some paediatricians were showing an interest in the care of premature infants, with the development of premature baby nurseries. In the United Kingdom, Mary Crosse (1900-1972) a paediatrician with obstetrical training, established the first premature baby unit at the Sorrento Maternity Hospital, Birmingham in 1931⁷. She emphasised the application of warming, humidity, nutrition and the meticulous individual nursing care of each infant⁸.

In Belfast, Frederick Allen (1898-1972), set up the first premature baby unit at the Royal Maternity Hospital (RMH) in 1927, and was also put in charge of the sister unit at the Jubilee Maternity Hospital in 1938 (**Figure 1**). Allen, the son of a grocer and a Queen’s graduate, was first appointed consultant paediatrician to the Royal Belfast Hospital for Sick Children (RBHSC)



Fig 1 Frederick Allen

¹ Dr Reid was a Consultant Neonatologist at the Jubilee and Royal Maternity Hospitals from 1977-2001.

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in 1924 and as physician-in-charge of infants at the RMH in 1927. In 1948 he became the first to hold the Nuffield Chair of Child Health at Queen's and the RBHSC. All of these posts he maintained until his retirement in 1963. His text, *Aids to the Diagnosis and Treatment of the Diseases of Children*, went through eleven editions up to 1962⁹.

At the Belfast City Hospital, the new Jubilee Maternity Hospital was opened in 1935. The previous maternity unit, named Ivy Cottage and founded in 1893, was converted to a neonatal unit for the Jubilee in 1948¹⁰. The neonatal nurseries at the RMH and Jubilee were among the earliest to be established in Britain and Ireland.

The National Health Service (NHS) was founded in 1948, bringing hope to a war-weary nation. Two paediatricians with an interest in newborn care were appointed consultants: Muriel Frazer at the Jubilee and Wilfred Campbell at the RMH.

Muriel Frazer (1911-2011) was educated at Victoria College and Queen's – graduating in medicine in 1936 (**Figure 2**). She was an able student and gained the MRCP in 1938 and the FRCSI in 1939. Blocked by a lack of surgical posts for women she turned to paediatrics. Before Dr. Frazer's appointment the neonatal unit at the Jubilee was under the supervision of Professor Allen – but his attention was directed mainly to the development of the children's hospital. Frazer proved to be a strong and determined leader; she placed babies born in the hospital in separate nurseries, with isolation facilities for premature and sick newborns. She admitted sick and premature infants born at home and in GP obstetric units outside the hospital, and also organised surgical treatment of infants under her care rather than transfer them to the children's hospital¹¹. She did not get on well with Professor Allen and, although she was also appointed to the RBHSC and the RMH, she later confined her work to the City and Jubilee hospitals. Both she and Allen preferred to steer their own units in their separate ways, as was often the case between the City and Royal hospitals.

Dr. Frazer had converted to Catholicism in her early twenties and attended the Mater Hospital for early morning devotional services; following which she did a round of the new babies in the maternity unit there, before returning to the City Hospital. The Mater Hospital did not develop a special care baby unit and infants needing intensive care were transferred to the Jubilee or RMH neonatal units.

As a junior doctor in the 1960s Mark Reid worked closely



Fig 2 Muriel Frazer

with Dr. Frazer and found her to be a good teacher and a helpful colleague. It was an honour to take over her position when she retired in 1977. Later the ward was named the Muriel Frazer Neonatal Unit. She died in 2011 at one hundred years.

Wilfred Campbell (1918-1990) went to school at Campbell College and graduated in medicine from Queen's in 1940 (**Figure 3**). In the Second World War he served as a medical officer in the Royal Navy with the Atlantic convoys and in the Far East. Upon his appointment in 1948 he reorganised the neonatal unit at the RMH. Working closely with the professor of obstetrics, Charles MacAfee (1898-1978), he coordinated the care of infants with rhesus isoimmunisation.



Fig 3 Wilfred Campbell

Rhesus Isoimmunisation

Campbell highlighted the interface between obstetrics and paediatrics in his review of haemolytic disease of the newborn at the RMH in the 1940s/1950s¹²:

“Haemolytic disease of the newborn is one of the best examples of a condition in the common ground where the spheres of the obstetrician and paediatrician overlap”.

Macafee and Campbell encouraged centralisation of cases of rhesus isoimmunisation in Belfast and by the mid-1950s this was largely achieved – with two-thirds of the provincial cases managed at the RMH and one-third at the Jubilee¹². The antenatal selection of patients for pre-emptive induction of labour was based on predictive factors that were, to a degree, arbitrary: previous perinatal outcome, rising anti-Rh antibody levels and, in late pregnancy, reduced fetal movements or an undefined alteration in fetal heart rate¹³. (As a medical student in the summer of 1963, TFB remembers the almost breathless silence during the professorial round in the open antenatal ward of the RMH as Professor Macafee bent over the patient's abdomen listening to the fetal heart rate with his ear pressed to a small Pinard fetal stethoscope. After about two minutes he straightened up and said “I think the fetal heart is a little weaker, we should induce labour tomorrow.” So, that was it, the ‘undefined alteration in fetal heart rate’). Following this plan for pre-emptive induction at RMH in the 1950s, Fisher found the fetal loss was 16% in those induced and 29% in those allowed to go into spontaneous labour at term¹⁴.

After the pathophysiology of rhesus haemolytic disease was delineated in the early-1940s, simple ‘top-up’ transfusion of the newborn was given to correct anaemia. This was



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of limited value as it did not reduce the levels of harmful anti-Rh antibodies and could precipitate heart failure. After Wallerstein¹⁵ in New York and Diamond¹⁶ in Boston refined exchange transfusion this became the mainstay of treatment and halved the neonatal death rate. Wilfred Campbell carried out the first neonatal exchange transfusion at the RMH in 1948¹².

Nonetheless, Campbell's nine-year review (1948-1956) at the RMH displayed the high perinatal death rate of Rh isoimmunisation; of 305 affected cases, 64 (21%) were stillborn, 30 (9.8%) neonatal deaths and 211 (69.2%) survived. The era of unlimited reproduction was also shown in the parity of the mothers: 51% were para 5 or above and 12.4% were para 9 or more¹².

A more accurate prediction of fetal prognosis became available following the work of William Liley (1928-1983) in Auckland, New Zealand. In 1961 Liley used serial amniocentesis to measure the level of bilirubin and from these results developed a graph that placed the risk to the fetus into one of three prognostic zones – mild, moderate or severe¹⁷. He followed this in 1963 with the first intrauterine fetal transfusion (IUFT), which was necessary when the fetus was severely affected but too premature for induction and delivery¹⁸. In Campbell's series, in the era before neonatal intensive care, only 3 of 35 (8.6%) of infants survived when delivered before 34 weeks¹².

By the mid-1960s serial amniocentesis was used in Belfast to assess the level of fetal risk. Charlie Whitfield (1927-2018), a Queen's medical graduate of 1950, was a consultant obstetrician, senior lecturer and reader at RMH from 1964 to 1974; during which time he led the management of Rh cases. He introduced his 'Action Line' which was based on two levels of amniotic fluid bilirubin levels superimposed on Liley's graph¹⁹.

The first IUFT in Belfast was carried out at the Jubilee in 1964²⁰, and the second at the RMH in 1965¹³. The numbers rose steadily through the late 1960s; at the RMH there were six IUFT in six patients in 1966, rising to 88 IUFT in 55 patients by 1970¹³. The overall perinatal loss from Rh isoimmunisation was reduced dramatically: 1948(57%), 1955(31%) and 1968(19%).

By the mid-1960s the prevention of Rh isoimmunisation using Rh immune globulin (RhIg) was established. Although some patients received it from 1968, it was not until 1971 that routine postpartum prophylaxis with RhIg was available throughout Northern Ireland¹³. The combination of available contraception and RhIg prophylaxis led to a marked reduction in the number of affected Rh cases delivered at the RMH: from 161 in 1968 to 36 in 1980¹³. The further application of RhIg prophylaxis in the antenatal period and for first trimester loss led to the theoretical prevention of all cases; although system failures continued to occur²¹.

The main paediatric involvement, after initial resuscitation,

was to monitor the neonatal bilirubin levels. In Belfast, guidelines were developed to direct the need for exchange transfusion – often required within two days of delivery. Exchange transfusions were time consuming, taking about two hours, and in the early 1970s there were some 150 performed each year. Phototherapy was introduced in the late-1960s and a local study showed that this did reduce the need for exchange transfusion²².

This obstetric/paediatric cooperation set the scene for improved perinatal care in the future. As the scope of neonatal care expanded Campbell was less involved in direct medical treatment, and by the 1960s he was content to oversee the junior staff providing clinical care in the unit – recognising their youthful grasp of the changing technological advances. He retired to Scotland in 1983.

Oxygen Therapy

When Frazer and Campbell were appointed in 1948 oxygen therapy in premature infants was unrestricted and associated with an increased survival rate²³. However, in 1951, the paediatrician Kate Campbell in Melbourne established the link between high concentration and prolonged oxygen therapy and retrolental fibroplasia²⁴.

At the RMH, Oliver Fisher (1921-1997) consultant lecturer in the department of child health, reviewed the local experience²⁵. The improved survival rates of infants weighing less than 3lbs (1360g) was shown over time as the unrestricted use of oxygen therapy increased: 1935 zero; 1947 21%; 1952 55%. The cost of this improved survival however was shown in 1951-1952, when there were eleven cases of retrolental fibroplasia in 109 surviving infants – seven of whom progressed to blindness. By late 1952, at the RMH, the maximum concentration of oxygen was reduced to 40% and the duration of its administration limited as much as possible. From 1954 there were no more cases of retrolental fibroplasia in that era²⁵.

Neonatology as a Specialty

Thus, by the middle of the twentieth century, the care and responsibility for the newborn passed from the obstetrician to the paediatrician – much to the relief of many obstetricians. The terms 'neonatology' and 'neonatologist' were coined by the Baltimore paediatrician Alexander Schaffer (1902-1981) in his 1960 text, *Diseases of the Newborn*. He used it to denote that portion of paediatrics concerned with the "art and science of the diagnosis and treatment of disorders of the newborn infant."²⁶

While the long-term care of the newborn fell to the paediatricians they were less involved with the neonate that needed immediate resuscitation at birth. It was Virginia Apgar (1909-1974), an obstetric anaesthetist in New York, who drew attention to the benefit of routine appraisal of each newborn and the potential need for resuscitation. Her simple system evaluated the condition of the baby by observing five

basic signs: colour, heart rate, respiration, reflex irritability and muscle tone²⁷. Each of these signs were scored as zero, one or two at one and five minutes after birth. The simplicity and practicality of the Apgar Score ensured its universal adoption in maternity hospitals, including those in Northern Ireland.

By the early-1960s junior paediatric staff were increasingly asked to attend 'high risk' deliveries with the potential need for resuscitation. The resuscitation skills were taught initially by the anaesthetic staff, followed by more structured simulation teaching sessions using plastic model dolls. As was the custom in that era, the youngest staff were taught by those above them in the junior ranks. Better resuscitation equipment was made available in delivery rooms: radiant heaters above the resuscitation table, laryngoscopes, endotracheal tubes, masks, and necessary medications. These basic but critical interventions - mainly the avoidance of hypoxia and hypothermia with rapid transfer to the neonatal unit - improved the outcome for vulnerable infants.

The appointment of Ivo John Carré (1920-2007) to the chair of child health in 1963 added impetus to the clinical and academic development of paediatrics in Northern Ireland. He was born in Guernsey to a farming family and studied medicine at Cambridge and St Thomas' Hospital, London - where he was stranded when his home island was occupied by the enemy during the Second World War. After qualification in 1944 he undertook paediatric training in England and Australia before his appointment as senior lecturer in child health at Queen's in 1956. When he took the chair in 1963, he set about establishing paediatric subspecialists and improving the academic credentials of the department. Although he had no training in neonatology, his subspecialty was gastroenterology with a career-long interest in oesophageal reflux, he recognised the need and, in 1973, appointed Garth McClure to the first joint university lecturer and hospital consultant post in neonatology (**Figure 4**).

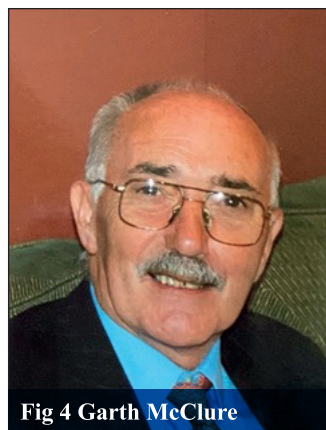


Fig 4 Garth McClure

The First Neonatologists

The 1970s saw the first appointment of consultants with specialised training in neonatology to the Jubilee and the RMH: Garth McClure (1973), Mark Reid (1977) and Henry Halliday (1979).

Garth McClure (b.1940), the son of a nurse, was brought up in Scotland and attended school in Fife. He graduated in medicine from Queen's in 1965, and took his paediatric training in Belfast with additional experience in neonatology

at Cardiff. After his appointment as consultant lecturer in 1973, he was keen to introduce new treatments and inspire others to develop the specialty. He brought energy and enthusiasm to the role and expanded both undergraduate and postgraduate teaching in neonatology - eventually being appointed to the Chair of Neonatology at Queen's. He was combative and a strong proponent of newborn care, and enjoyed taking on sceptical obstetricians to fight for the newborn cause. In 1993 he was elected president of the British Association of Perinatal Medicine. He retired in 2002.

Mark Reid (b.1937) represented Bangor Grammar School as head boy and as captain of the school rugby team (**Figure 5**). He qualified at Queen's in 1962 and undertook paediatric training in the Belfast hospitals. In 1968 he was awarded the Samuel Hazlett Browne Scholarship from Queen's to spend a year at the neonatal intensive care unit at the Toronto Hospital for Sick Children - this unit being at the forefront of assisted ventilation techniques for the newborn. He returned to Belfast as a senior registrar in 1969. In 1971 he was appointed consultant paediatrician to the new Craigavon Hospital and stayed there until his appointment as consultant neonatologist at the Jubilee and RMH sites in 1977. Reid was president of the Irish Perinatal Society in 1979. He retired in 2001.



Fig 5 Mark Reid

Henry Halliday (1945-2022) went to school at Belfast Royal Academy (**Figure 6**). He was a strong tall man who played rugby for his school and for the former pupil's side when he was a junior doctor. He graduated from Queen's in 1970 and did his paediatric training in Northern Ireland. He then spent three years subspecialty training at the Rainbow Babies and Children's Hospital in Cleveland (1976-78) and in the cardiovascular research unit at the University of California, San Francisco (1978-79). It was here that he worked with Dr. John Clements, one of the foremost authorities on pulmonary surfactant -



Fig 6 Henry Halliday



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which became a lifelong focus of Halliday's research²⁸. He returned to Belfast in 1979 to a consultant post at the RMH.

Halliday was a strong advocate of evidence-based medicine and led many of the international randomised clinical trials on surfactant use, to which the Belfast group contributed. His academic output was prodigious with more than 400 peer-reviewed publications. In 1992, he was appointed Honorary Professor of Child Health at Queen's. He held a number of prominent positions, including: President of the European Society for Paediatric Research (1997); President of the European Association of Perinatal Medicine (2006) and Co-Founding Editor of the journal *Biology of the Neonate*, now known as *Neonatology* (2004). Recognition of his contributions to neonatology included the Maternité Prize from the European Association of Perinatal Medicine (2010) and, in 2021, the James Spence medal – the highest honour awarded by the Royal College of Paediatrics and Child Health. Among the tributes paid after his death in 2022 it was said: "He demonstrated that absolute scientific rigour and humanity can go together".^{29,30}

The creation of this third consultant neonatologist post at the RMH was stimulated by the increasing burden of neonatal intensive care cover by McClure and Reid. The final straw came when, after three weeks of single-handed cover with repetitive night call, Reid, unannounced, went to see the Medical Officer of Health, Dr. Bob Weir, at his home. He outlined the untenable position and said he and McClure would both resign if a third position was not created. McClure was on holiday and unaware that that he was threatening to resign, but in retrospect agreed with the tactic. To his credit, Weir acknowledged the situation and was able to find the funds to support Halliday's appointment.

Developments in Neonatal Care

Infants and children had been receiving intensive ventilator care in the Children's Hospital since 1966, organised by paediatric anaesthetists Harold Love (1920-2010), Gerry Black (1925-2019) and Sam Kielty. However, ventilator treatment in the neonatal units of the Jubilee and RMH did not start until 1978, when Reid and McClure were able to muster the necessary equipment and personnel resources; the addition of which transformed the special care baby nursery into a neonatal intensive care unit (NICU). It took some diplomacy to gain acceptance of ventilators in the neonatal units; ultimately the Children's Hospital staff recognised that the number of neonates needing ventilator care would overwhelm the Children's ICU. The necessary interhospital cooperation was aided by Reid's appointment, which included one session a week at the Children's Hospital ICU.

The 1970s brought major technical advances that improved clinical care of the newborn - particularly very small infants. These included: improved ventilators with methods to deliver continuous positive airway pressure (CPAP) and positive end expiratory pressure (PEEP); apnoea alarms; infusion pumps; phototherapy; parenteral nutrition and micro methods to

assess blood biochemistry, which obviated the need for venipuncture. Micro blood samples permitted measurement of arterial oxygen tension, to be replaced by the even less invasive transcutaneous methods in the 1980s³¹. Incubators were improved with better temperature control and precise oxygen delivery. Transport incubators for interhospital transfer were developed. Cot-side ultrasound, particularly of the brain, heart and lungs, led to earlier and more focused care of each infant.

By the late-1970s, other than for invasive procedures, staff masks and gowns were abandoned. More important was the change allowing parents, formerly confined to looking through the corridor windows, access to the units to see and touch their babies. This improved communication with the medical staff and gave nurses the opportunity to 'translate' some of the medical terminology for the parents. Another important step was the creation of a separate baby chart; confirming that babies were patients in their own right. This also facilitated long term follow up and it was adopted province wide.

Respiratory Distress Syndrome and Surfactant

In 1967 Reid and colleagues reviewed the outcome of all premature infants (<2500gm) looked after at the Royal Maternity Hospital neonatal nursery over the twelve-year period, 1952-1963. There were 3829 such infants with a survival rate of 83.1%³². The commonest cause of death (35.6%) was 'respiratory disorders'. Comparing the two six-year epochs, 1952-1957 and 1958-1963, there was no significant difference in the mortality rates, reflecting the relative lack of advances in neonatal care during that period.

Most premature infants who die a few days after birth show hyaline membrane disease (HMD) of the lungs at post-mortem examination. Because HMD is a pathological diagnosis, the term respiratory distress syndrome (RDS) came into clinical use³³. In 1959, it was shown that HMD was due to a deficiency of surfactant in lung fluid³⁴. The assessment of fetal lung maturity via amniotic fluid analysis using the ratio of lecithin to sphingomyelin (L/S ratio) was introduced by the American pioneer neonatologist, Louis Gluck (1924-1997)³⁵. As a proxy for adequate neonatal lung surfactant this test came into common use as a guide for induction of labour by obstetricians.

The next logical step was to attempt surfactant replacement via the endotracheal tube in premature infants with RDS. A variety of synthetic and animal lung-derived products were tried and after early setbacks there was success with a calf lung extract³⁶. There followed several randomised controlled trials (RCT); the main contenders in the United States being the synthetic product Exosurf and the calf lung-derived Survanta.

In Belfast, Halliday led the group's RCT of a locally produced synthetic surfactant, Turfsurf, also known as the 'Belfast surfactant'. Unfortunately, the results were disappointing³⁷.

Halliday, however, developed contacts with the Karolinska University Hospital in Stockholm. In 1984 he spent a month there and was impressed by the results of animal studies with their porcine-derived surfactant, Curosurf. Belfast's advantage was the provision of a large clinical base for enrolment in the subsequent European RCTs of Curosurf. The results were very successful and the impact of exogenous surfactant on reducing the morbidity and mortality of RDS has been enormous^{38,39}.

Perinatal Collaboration

In the 1970s, with the advent of amniocentesis, ultrasound and fetal heart rate (FHR) monitoring, obstetricians started to regard the fetus as a patient whose well-being could be assessed and occasionally treated. Induction of labour increased and ultrasound enabled the diagnosis of some fetal anomalies, ensuring that plans for the appropriate place of delivery and early neonatal treatment could be put in place.

The relationship between obstetrics and neonatology strengthened in the 1970s/1980s. Jack Pinkerton (1920-2013), professor of obstetrics from 1963 to 1985 was keen to promote perinatal research. Two junior obstetric lecturers with additional perinatal training, Knox Ritchie (1944-2022) and Jim Dornan (1948-2021), provided the main impetus for collaborative clinical endeavour and research. One result of this collaboration was a review of the provision and outcome of neonatal care in the province, which was published in the *British Medical Journal* in 1978⁴⁰. It detailed the poor state of neonatal care in Northern Ireland, where there were no less than 42 units of variable size delivering babies. Moreover, the province had the second highest rate of neonatal death in Europe; a disgraceful distinction in an NHS that prided itself as being one of the best in the world. The paper sparked a reaction at the Department of Health which set up a committee, composed of representatives from obstetrics, paediatrics, midwifery and administration, to advise on the future development and organisation of maternity services. The report (The Advisory Committee on Neonatal Mortality and Handicap, 1979/1980) recommended fewer obstetric units, centralisation of care, enhanced staffing and financing to facilitate these developments. These recommendations were slow to be enacted, as we were warned by the Chief Medical Officer at the time. This slow progress was due to a degree of political cowardice (closing small clinical units is very unpopular), and a failure by medical professionals to adequately explain the advantages of care and delivery in better staffed and equipped units. However, over several decades the number of hospitals providing complete maternity care has fallen from 42 (1978) to seven (2024).

Another major factor leading to improved perinatal outcome was the use of antenatal corticosteroids to reduce the risk of RDS in premature infants, and the subsequent finding of reduced risks of intraventricular haemorrhage and necrotising enterocolitis⁴¹.

Over the thirty years, 1962 to 1992, the perinatal mortality

rate in Northern Ireland fell from 38/1000 to 8/1000^{42,43}.

The 1970s/1980s also saw the expansion of other subspecialties supporting neonatal care. In cardiology, Frank Pantridge (1916-2004) and George Patterson (1927-2013), provided diagnostic and treatment services at the Children's Hospital since the 1950s. These were refined and made available to the newborn with the appointment in 1976 of Connor Mulholland who, after additional training in Toronto, became the first fulltime paediatric cardiologist. He was later joined by Brian Craig and Frank Casey. Surgical services at the Children's Hospital were provided by Stephen Brown, Victor Boston and Stephen Potts. (The first ligation of a patent ductus arteriosus was performed in 1947 by Barney Purce (1891-1950), surgeon at the Royal Victoria Hospital⁴⁴). Neonatal imaging was made possible by portable X-ray equipment in the 1960s and, since 1968, this was overseen by Paul Thomas. He was later joined by Louise Sweeney with expertise in ultrasound. Other contributors to the understanding and development of neonatal medicine included the anatomist, Cowan Meban, who assisted with the early surfactant studies, and John Edgar Morison (1912-2007), with his extensive and detailed work on perinatal pathology⁴⁵⁻⁴⁷.

Nursing

Most medical innovation and progress stand on the shoulders of the nursing staff. In all the units we worked in the nurses were keen to innovate and improve the care of their babies. Without their sustained commitment and willingness to adopt and with skill and compassion apply the new technical advances, the improved neonatal outcomes would not have been possible. It is impossible to name all the leading nursing figures who worked in neonatal intensive care but those such as Marie Crothers, Annemarie Donaghy and Elsie Faux in the Jubilee; Liz Marks, Phil Farrell, Norma Sittlington and Pauline Armstrong in the RMH; and Sadie Greer and Liz Douglas at the Ulster Hospital are a few names among many who deserve full-hearted praise.

Continuing Professional Development

The trio of new neonatologists decided to produce a text on neonatal intensive care to assist the nursing and junior medical staff working in this new specialty. Thus, in 1981, the first edition of *Handbook of Neonatal Intensive Care* by HL Halliday, BG McClure and M McC Reid was published by Bailliere, Tindall and Cox (Figure 7). The book was a success and further editions followed in 1984, 1989 and 1998. The last edition was co-edited by Angela Bell and

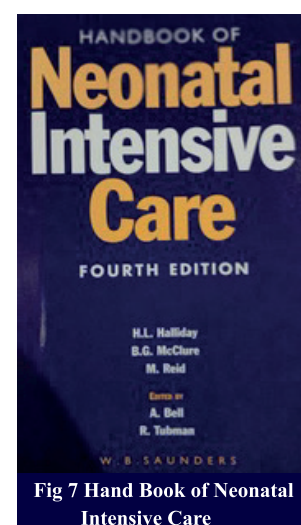


Fig 7 Hand Book of Neonatal Intensive Care



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Richard Tubman – former trainees. An Italian edition was published in 1990.

In the 1960s paediatric training entailed years of junior hospital posts, but the required postgraduate examination could only be taken in adult medicine at one of the Royal Colleges of Medicine. It was not until 1999 that the newly established Royal College of Paediatrics and Child Health was able to administer a complete postgraduate exam in paediatrics. So, the first three neonatologists took their royal college certification in adult medicine.

Junior doctors in the postgraduate paediatric training programme rotated through the Belfast NICUs from the 1970s. Some chose a career in neonatology, and over the last twenty years of the twentieth century they produced several MD theses and a plethora of papers on neonatal medicine, including: surfactant trials, nutrition regimes, iron metabolism, infants of diabetic mothers, gastric aspiration, chronic lung disease, energy expenditure and EEG studies⁴⁸⁻⁵³. Some of the 'graduates' of the programme include: Angela Bell and Anne Black who set up the NICU in the Ulster Hospital to care for all but the smallest of babies. Richard Tubman became the fourth neonatologist at the Jubilee and RMH in 1993 and established a regional neonatal transport service. Desi Brown, at Altnagelvin Hospital, developed a computer-based system to link infants with possible cardiac problems with cardiologists in Belfast and John Jenkins, along with Jarleth McAloon and Joe Lim, developed the NICU at the Antrim Area Hospital.

By the early 2000s, with the closure of smaller maternity units, there were seven hospitals providing full maternity care. The South Western Hospital in Enniskillen and Daisy Hill in Newry had special care baby units; the other five hospitals (Antrim, Craigavon, Derry, Ulster, and the now Royal Jubilee Maternity Hospital) had NICUs. The number of neonatologists expanded from the original three in 1979 to more than twenty. In 2000, the decision was taken to amalgamate the two units in central Belfast, Jubilee and RMH, after a public airing of the relative merits of both hospitals in the media. The decisive factor was the proximity to the Children's Hospital, and twenty years later the new Royal Jubilee Maternity Hospital was built on the Royal site.

Neonatal Associations

In 1976, Peter Dunn (1929-2021) the first neonatologist in Bristol, wrote to all the teaching hospitals in Britain and Ireland and found only twenty-one paediatricians who devoted a majority of their work to neonatology. This group of twenty-one, including Garth McClure and Mark Reid, became the founding members of the British Paediatric Perinatal Group, which had its first meeting in Bristol in 1976. In 1985 it became the British Association of Perinatal Medicine and had expanded to include a multidisciplinary group of obstetricians, midwives, neonatal nurses, obstetric anaesthetists and paediatric surgeons⁵⁴.

The Irish Perinatal Society (later to be called the Irish Neonatal Society) was established in 1976. Garth McClure and Mark Reid were founder members, and Reid was elected president in 1979. This was one of the Irish medical societies founded and maintained during the 'troubles' which helped foster collaboration and friendship during this fraught political era.

The trio of early neonatologists were made honorary members of the Ulster Obstetrical and Gynaecological Society and became frequent contributors to the scientific programmes.

In Belfast, neonatal mortality has fallen from 40/1000 in 1950, to 28/1000 in 1970, to just over 3/1000 today^{32,40,42,43}. Factors other than medical care have contributed to this, including: better housing, socio-economic conditions and smaller families. From the midwifery and obstetric viewpoint there are three morbid intrapartum factors that should be avoided during the transition from fetus to neonate: infection, hypoxia and trauma. With modern neonatal care, if these three factors can be avoided, the outlook for long-term infant survival without disability is very good. In the 1960s, when we started as junior doctors in the RMH, babies born in the 28 to 34 week gestation group had little or no chance of survival (births less than 28 weeks were classified as 'abortion' or 'miscarriage') – now, most are assured of long-term intact survival.

The basic principles of neonatology were and remain: keep the baby warm, pink, fed and clean. The big change with modern neonatal intensive care is that this has become feasible for very small infants – less than 24 weeks gestation. Pushing the boundaries of the age of viability continues, with efforts to keep these infants in a stable physiological milieu. The main worry is the potential for long-term disability in these tiny patients. Achieving a balance between what is possible and what is appropriate remains a significant ethical issue.

Key words:

History, Neonatology, Perinatal Medicine.

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Game Changers

NEW TREATMENTS FOR HEART FAILURE WITH PRESERVED EJECTION FRACTION

Heart failure with preserved ejection fraction (HFPEF) accounts for about half of all new heart failure diagnoses. Until 2022 the only treatment was loop diuretics for symptom relief. In the short time since, several new therapeutic options have emerged, all of which were initially designed for other clinical indications:

1. Sodium-glucose co-transporter 2 (SGLT2) inhibitors have been used in diabetic patients since 2012. In 2022 two major trials in HFPEF patients showed that both dapagliflozin and empagliflozin substantially reduce the risk of hospitalization, resulting in a Class 1 recommendation for both agents for the treatment of HFPEF.¹

2. Glucagon-like peptide-1 (GLP-1) analogues have been used in diabetic patients for 20 years and are now very familiar to the public because of their off-label use by celebrities who want to lose weight. Semaglutide has been shown to improve symptoms, exercise capacity and weight loss in patients with obesity and HFPEF while substantially reducing NT-proBNP levels^{2,3}. Tirzepatide, a dual agonist of GLP-1 and glucose-dependent insulinotropic polypeptide receptors, also significantly improves symptoms in patients with obesity and HFPEF, while reducing the likelihood of a worsening heart failure event.⁴

3. Finerenone, a nonsteroidal mineralocorticoid receptor antagonist was initially developed to reduce the risk of renal complications in type 2 diabetes. It has subsequently been shown to reduce the risk of heart failure events in patients with HFPEF⁵ and it is now licensed to treat the condition in the United States of America.

4. Mavacamten, a cardiac myosin inhibitor, substantially reduces left ventricular outflow tract obstruction in patients with hypertrophic cardiomyopathy. In a phase 2 trial, mavacamten improved echocardiographic markers of LV diastolic function and reduced plasma NT-proBNP and troponin levels in patients with HFPEF⁶. A phase 3 randomised clinical trial is underway.

Outcomes for patients with heart failure with reduced ejection fraction (HFREF) have improved dramatically with the emergence of “four pillars” of evidence-based treatment.

So far none of the new HFPEF treatments has reduced mortality but the accumulation of evidence above predicts a similar enhancement of therapeutic options for this growing population of patients.

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Clifton House, Belfast, the foundation stone of which was laid on 7 August 1771. It was originally opened as the Belfast Poor House and today is the city's oldest working building. Owned by Belfast Charitable Society, the building has links to pioneering local physicians including Dr William Drennan.

Image courtesy of Clifton House.



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- *Example:* Devlin LA, Price JH, Morrison PJ. Hereditary non-polyposis colon cancer. *Ulster Med J* 2005;**74(1)**: 14-21.

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What will it look like? iREACH Health, Belfast.

iReach Health is a £64m integrated clinical research innovation centre led by Queen's University Belfast in partnership with the Belfast Health and Social Care Trust and Health and Social Care Research and Development Division, opening in Spring 2027.

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