Challenges and opportunities in the care of chronic subdural haematoma: Perspectives from a multi-disciplinary working group on the need for change

The Improving Care in Elderly Neurosurgery Initiative (ICENI)

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**Key Words**

* Chronic Subdural Haematoma
* Perioperative medicine
* Quality improvement
* Review

**Word Count (excl abstract): 3470**

## Abstract

## Introduction:

A chronic Subdural Haematoma (cSDH) is a collection of altered blood products between the dura and brain resulting in a slowly evolving neurological deficit. It is increasingly common and, in high income countries, affects an older, multimorbid population. With changing demographics improving the care of this cohort is of increasing importance.

## Methods:

We convened a cross-disciplinary working group (the ‘Improving Care in Elderly Neurosurgery Initiative’) in October 2020. This comprised experts in neurosurgical care, as well as a range of perioperative stakeholders. An Implementation Science framework was used to structure discussions around the challenges of cSDH care within the United Kingdom. The outcomes of these discussions were recorded and summarised, before being circulated to all attendees for comment and refinement.

## Results:

The working group identified four key requirements for improving cSDH care: (1) data, audit, and natural history; (2) evidence-based guidelines and pathways; (3) shared decision-making; and (4) an overarching quality improvement strategy. Frequent transfers between care providers were identified as impacting on both perioperative care, as well as presenting a barrier to effective data collection and teamworking. Improvement initiatives must be cognisant of the complex, system-wide nature of the problem and may require a combination of targeted trials at points of clinical equipoise (such as anaesthetic technique or anticoagulant management), evidence-based guideline development, and a cycle of knowledge acquisition and implementation.

## Conclusion:

The care of cSDH is a growing clinical problem. Lessons may be learned from standardised pathways of care such as those as used in hip fracture and stroke. A defined care pathway for cSDH, encompassing perioperative care and rehabilitation, could plausibly improve patient outcomes but work remains to tailor such a pathway to cSDH care. The development of such a pathway at a national level should be a priority, and the focus of future work.

# What is a chronic subdural haematoma and what is the case for change?

A chronic subdural haematoma (cSDH) is a collection of altered blood products that can form between the dural membrane and the surface of the brain. Most commonly occurring in older, medically complex cohorts [1–4], cSDH is strongly associated with age [1,5–7]. It can lead to neurological impairment through localised perfusion deficits secondary to the mass effect of the cSDH [8,9] or through direct distortion of key motor pathways[10]. Symptoms may mimic a stroke, including hemiplegia or gait disturbance, headache and worsening cognition[2]. Subacute and progressive deficits typically occur over days to weeks, although more acute and/or transient presentations are also possible [8] (**Figure 1**). Current incidence estimates range from 1.7/100,000/year[5] to 48/100,000/year[11][12], but several longitudinal studies have demonstrated increased incidence over time, likely driven by aging populations, increased detection linked to access to imaging, and use of anticoagulation [7,11,13][14,15]. Shifting demographics may lead to significant increases in case numbers over the coming decades[12,16].

Some medical therapies for cSDH have been proposed and trialled[17], and procedures such as middle meningeal artery embolization are under investigation[18], but surgical evacuation currently remains the mainstay of treatment for symptomatic cSDH. Approximately 13,000 cSDH operations were conducted in England between 2013 and 2019 [19]. However, surgery is associated with in-patient morbidity and mid-term mortality [2,3] and significant hospital stay [17]. The rising burden of disease and the potential for associated morbidity and mortality makes improving the care of patients with cSDH a healthcare priority.

Progress in improving care has in part been hindered by weaknesses in the evidence base for cSDH. It is a relatively small research field, andactivity has largely been focused on the delivery of surgery itself. This has paid dividends in terms of defining best practice for surgical intervention [17,20], but little is known of what happens to those not accepted for surgery [2], including how they are managed, by whom, and their likelihood of going on to being re-referred or discharged – though two studies demonstrate higher mortality (44% *v* 17%) in non-operated vs operated patients at 4 weeks, but the numbers are small and likely to be distorted by unmatched frailty, age, and comorbidity characteristics between cohorts[13]. Likewise, other aspects of perioperative management remain under-developed and poorly specified[21]. For example, extended rehabilitation models are not standardised, and care is typically provided by non-specialist professionals outside of designated neurosurgical centres. The experiences of patients and families at different points in the care journey and their priorities for outcome measures remain neglected as areas of study. These gaps in the evidence pose challenges for determining “what good looks like”[22] in the care of people with chronic subdural haematoma.

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# What could good look like?

Important learning is available from other surgical fields that have improved care, including hip fracture fixation [23] and emergency laparotomy[24]*.* In hip fracture, for example, clear evidence has emerged of the role of integrated working in dramatically reducing mortality [25]: hip fractures are now co-managed between orthopaedic surgery and specialists in geriatric medicine [23]. These pathways have similarities with cSDH in that they serve a population of older, frail patients requiring emergency surgical intervention. However, the care of patients with cSDH is characterised by further additional complexities [2]. First, not all people with cSDH require or will benefit from surgery. In the UK, around 30% of patients referred for a neurosurgical opinion will not be accepted for surgery, in the main (~70%) owing to a lack of symptoms[2]. Second, of those accepted, between 47% and 90% of UK patients are transferred between hospitals [2][3]. These transfers of care create significant challenges to communication, safety, flow, and patient experience[26]. Successfully improving pathways requires clear understanding and design of the entirety of the patient journey between providers and relinquishing a siloed approach, [26]. Encouragingly, an audit of the only published example of an integrated care pathway for cSDH to date found that it significantly increased the number of patients undergoing surgery within 24 hours of admission. [27]

Much valuable learning is also likely to be had from examining pathways outside of surgery, including stroke. Stroke care has evolved significantly in recent years, supported not only by a high quality national clinical audit but also by a highly organised framework of acute referral pathways, crossing primary, secondary and tertiary settings, including treatment and rehabilitation, alongside pre- and acute stroke management. Care today is coordinated effectively through a multidisciplinary team comprising physicians, specialist nurses, anaesthetists, critical care physicians, neurosurgeons, and interventional radiologists, within and between centres [28]. With the emergence of interventions such as thrombectomy and the protocolisation of referral for decompressive hemicraniectomy, liaison between referring hospitals and specialist neuroscience centres for stroke has become increasingly routine. Furthermore, the overlap in presenting symptoms between cSDH and acute stroke (**Figure 1)** mean that it is possible that patients may first present to a local centre’s stroke service (**Figure 2**).

The improvements seen in emergency surgery and stroke offer promising precedents, but seeking to reproduce these successes for cSDH will require specific and sustained attention.

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# Improving care of chronic subdural haematoma

Recognising the distributed and complex nature of the care needed for people with chronic subdural haematoma, and the requirements for multidisciplinary expertise, the *Improving Care in Elderly Neurosurgery Initiative* *(ICENI)*[29]was formed in 2019. A multi-disciplinary group of UK stakeholders, including representatives from across the cSDH perioperative care team, patient advocacy groups, and national experts in healthcare improvement, ICENI is exploring the possibility of understanding, designing, and implementing an integrated pathway for cSDH management. Such a pathway should draw on lessons learned from design and implementation of other care pathways, principles of implementation science, systems thinking[22], and a range of diverse perspectives.

Implementation science – the “*dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system*” – offers a useful framework for structuring thinking in this area [30].Various approaches and models have been proposed, including Straus’s Knowledge to Action Cycle **(Figure 3)**[30]. In this model, a key starting point is the identification and definition of knowledge gaps (‘Determine the Know/Do Gap’ in Figure 3), establishing both the requirement for new knowledge, and subsequent improved application of existing knowledge.

Following a meeting of national stakeholders in October 2020 and using this framework, the ICENI collaborative identified three key requirements for improving care of cSDH **(Table 1)** as well as the need for an integrated quality improvement strategy. Here we summarise these requirements, with reference to their respective evidence base and highlighting the key knowledge gaps.

# Data, audit, and natural history

A first challenge in improving care of cSDH is the absence of high-quality data. In other areas of clinical practice, disease registries and large-scale clinical audits have had an important role in improving care over time, helping in systematic assessment of care and in identifying areas for improvement. For instance, the national hip fracture database (NHFD)[31] has been linked to substantial reductions in mortality[32], supported by best practice tariffs [33].

Some disease specific-registries for neurosurgical conditions – such as that for ventriculoperitoneal shunts[34] – already exist, and could potentially be adapted to accommodate cSDH if a consensus view on minimum datasets and quality indicators could be achieved[35]. With appropriate information governance, a system that could capture relevant processes and outcomes different stages of the patient journey (e.g. referring and neuroscience centres) may also be possible. As well as helping to guide practice, such a registry, alongside a national audit program analogous to the National Hip Fracture Database (NHFD)[31] or the National Emergency Laparotomy Audit (NELA)[36], would help improve understanding of the epidemiology of cSDH by providing a consistent case definitions and address issues with use of current diagnostic and operative codes[37]. This is a crucial requirement, as routine hospital coding currently crudely categorises all subdural haematoma as either traumatic or non-traumatic based on the International Classification of Diseases (ICD) framework. This distinction is not reflective of the clinical phenotype of cSDH[38], and has shown poor sensitivity and specificity for identifying cases in large scale registries[37]. Improved, standardised, case-definitions could not only aid ongoing audit but could also clarify understanding of population epidemiology[12], including outcomes for patients with cSDH who do not undergo surgery and who may be missing from surgical databases.

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# Evidence-based guidelines and integrated care pathways

Much can be done to support the specification of good practice for care of people with cSDH. In this section we identify three areas along the patient journey where discussions highlighted how current practice could benefit from being defined in an integrated manner. In so doing, we also identify further crucial evidence gaps, including points of equipoise that may be amenable to a future randomised controlled trial.

## Pre-surgical optimisation

Presentation of cSDH is characterised by clinical variability, with high rates of baseline disability, comorbidity, and polypharmacy[2,3], and frailty. These factors have clear implications for both anaesthetic and surgical management, and, as demonstrated in other clinical areas, are consequential for outcomes [23] [24]. In a nationwide survey of UK operative practice, the median modified Rankin score (mRS) at the point of admission was 3 (indicating moderate disability) with over 40% of patients receiving anticoagulant and antiplatelet medications[2]. Over 60% of patients in one study had an American Society of Anesthesiologists (ASA) score of 3 (severe systemic disease) [3] with high rates of cardiovascular and respiratory disease [2,3]. Although age has been related to outcomes[39], including discharge Glasgow Outcome Score (GOS)[40] and mortality at 90 days [1] it is plausible that this may reflect underlying rates of comorbidity or frailty. Application of a hospital frailty index to a centralised national health service (NHS) database[41] demonstrated that 50% of examined neurosurgical patients were classed as severely frail, with these patients exhibiting longer length of stay[42]. Further, direct evidence may come from the embedding of frailty assessment into specialist services such as neurosurgery that is being supported by the Specialised Clinical Frailty Network (SCFN)[43]. The importance of appropriate perioperative management of the frail patient is reflected in recent guidelines[44].

How best to optimise candidates for cSDH surgery across hospital sites is an important concern. Work from one specialist centre suggests that a policy of instigating medical optimisation in referring centres does shorten time to surgery but does not appear to affect outcome at the point of neuroscience centre discharge [27], but numbers were small. Whether to instigate medical optimisation in the referring hospital or upon arrival in the neurosciences centre is a key unknown, and may well be dependent on the facilities available in both hospitals. Experience from the fractured neck of femur pathway[45] is suggestive of trade-offs in terms of timing between pre-optimisation and definitive management, with delays to treatment resulting in greater deconditioning and worse overall outcome. Currently available data demonstrates that longer time to surgery is associated with longer length of stay and a non-significant (*p = 0.06)* trend towards worse functional outcome at discharge when waits are longer than 7 days[46]. The impact of repeated pre-operative cancellations should also be considered, given the evidence of a relationship between nutritional status and outcome after cSDH[47].

A key stage of perioperative optimisation is the management of antiplatelet and anticoagulant medication. Approximately 45% of patients who present with cSDH are taking some form of anticoagulant or antiplatelet agent[2,3]. This may be a critical source of morbidity, as highlighted by a recent population study using the Medicare database, which identified that patients were at a fourfold increased risk of an ischaemic stroke in the four weeks after sustaining a cSDH[48]

Perioperative management of antithrombotic agents draws heavily on findings from related conditions, or observational data[49] and requires individualisation based on patient, surgical, and pharmacological factors. Broadly, management consists of efforts to reverse antithrombotic effects or delay surgery, where possible, until drug levels have cleared[50]. Duration between cessation of antiplatelet agents and surgery is associated with recurrence rates in observational data, with recurrence rates appearing comparable after three days[51]. Platelet transfusion appears to be common practice when surgery cannot be delayed, but this practice lacks a robust evidence base[52].

 In a national survey of UK practice, reversal strategies included platelet transfusion (administered in approximately 30% of those receiving aspirin[2]), delayed transfer for surgery in non-urgent patients(~8% of referrals[2]), and use of clotting factors and vitamin K. Importantly, patients in this study were recruited in 2013-2014 and only 1% of patients received ‘other’ anticoagulant or antiplatelet drugs (including Direct acting Oral Anticoagulants – DOACs, such as the Factor Xa and direct thrombin inhibitors). This figure was approximately 5% in a trial cohort recruited between 2015 and 2019[17] but at a population level, use of these drugs has increased dramatically over this time period[53].

Specific reversal agents include idaricuzumab[54] for the reversal of dabigration (an oral direct thrombin inhibitor), prothrombin complex concentrate (for warfarin and off licence management of bleeding associated with oral factor Xa inhibitors despite very low quality evidence[55]), and Andexanet alfa for the reversal of Xa inhibitors apixaban and rivaroxaban. However, andexanet alfa is not currently recommended by NICE[56] or the British Society for Haematology (BSH)[57] for the perioperative management of intra-cranial haemorrhage which is at variance with the summary of product characteristics[58] and guidance from the Scottish medicines compendium[59].

## Surgery and the immediate post-operative period

The surgical procedure for cSDH is now well characterised[20,60], with the use of subdural drains and burr-hole drainage associated with a normalised risk of death over 5 years compared to an age and sex matched population[61]. Alternative techniques – such as twist drill craniostomy or craniotomy –may have roles in specific circumstances[60]. However, uncertainty persists around optimal anaesthetic technique. Intraoperative events do not appear to be associated with surgical outcome in retrospective datasets[3], but questions endure as to whether surgery under general (GA) or local anaesthesia (LA) is the optimal choice.

Data from both the UK and elsewhere suggest a majority of cases are performed under GA[2,62] although a retrospective study examining outcomes in nonagenerians highlighted a high (93%) rate of LA use in a Scandinavian cohort[1]. No robust randomised controlled trials examining this issue exist and our discussions in ICENI highlighted likely equipoise. Questions around patient selection as well as training provision for anaesthetists and surgeons remain unresolved. Although only 3% of operations were performed by consultant neurosurgeons in one national audit[2] data appears to suggest that grade of surgeon is not associated with outcome[63] although no equivalent data exists regarding seniority of anaesthetist. Consideration of the required anaesthetic expertise and appropriate training should be a priority for future work.

National data from across the UK also highlights heterogeneity in immediate postoperative management, with varying periods of bed rest, routine post-operative imaging, and the use of high-flow oxygen[2]. Care is normally conducted on a neurosurgical ward before referral for ongoing rehabilitation, or repatriation to the referring hospital occurs. Delays in repatriation can cause pressures on limited neurosurgical bed numbers[64]. A crucial issue to address in this phase of care concerns decision-making surrounding antithrombotic drugs; the literature fails to offer consensus on the optimal restarting of antithrombotic drugs in patients with cSDH[65], despite suggestions from retrospective data that timing of resumption may significantly alter the occurrence of post-operative thrombotic and haemorrhagic complications[66].

## Rehabilitation

A key area of concern in cSDH is the availability of appropriate rehabilitation. The solution to this is far from obvious, with questions as to the most appropriate models and locations of care. The pressures on neurosurgical beds[64] appears to render rehabilitation on an acute neurosurgical ward unfavourable, but needs to be considered in light of length-of-stay data[3,19] and the risks of prolonged immobilisation on recovery in other surgical settings. In the UK, rehabilitation services may be either locally or nationally commissioned[67] depending on patient complexity. ‘Hyper-acute rehabilitation’ can be commenced pending an appropriate referral and acceptance to either specialist inpatient or community services[67], but the appropriate model for cSDH requires design and testing.

Any future integration and streamlining of rehabilitation pathways for cSDH patients will require improved understanding of rehabilitation requirements at the point of discharge from acute hospital beds across both operative and non-operative cohorts. Again, existing models may provide valuable lessons: both stroke and major trauma rehabilitation have been integrated into their respective care pathways in an effort to address the challenge of linking tertiary and secondary centres. Arguably, this dichotomising of care between centres could also create challenges in timely recognition and identification of post-operative complications such as recurrence as well as rehabilitation difficulties. However, detailed understanding of events following repatriation is currently lacking.

## Shared decision-making

Good practice in shared decision-making and communication between professionals and patients and their relatives is a priority for cSDH. However, very little is known about patients, families’ and clinicians’ experiences of these discussions or their understanding of different points in the patient journey, including temporality of intervention and likelihood of transfer. Many conversations are likely to be conducted by non-specialist clinicians from acute medical or emergency medicine backgrounds, in non-specialist hospitals. However the absence of validated risk stratification tools [68], a lack of standardised UK criteria for acceptance for surgery, and absence of data on patients’ and families’ experiences of current care practices means that referring clinicians may face significant uncertainties in referral and decision-making processes. Pre-surgical discussions and shared decision-making with patients and family members, including communication of the rationale for either proceeding to surgery or opting for a conservative approach, may therefore be very challenging. In other surgical cohorts the role of pre-operative frailty assessment has shown utility in identifying higher risk patients, and further work on the importance of this in CSDH may be of use. Further complexity may arise in the future as the findings of ongoing randomised controlled trials are focusing on medical therapies as both adjuvant or true conservative management[69] become integrated into practice.

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# A quality improvement strategy

cSDH represents a significant and growing clinical burden where significant knowledge gaps exist **(Figure 4)**  at every level. Current cSDH expertise is focused largely in tertiary neurosciences centres, complicating both effective acute and long-term management of the condition, while overlooking incidental disease. Research has remained largely narrowly focus on emergent treatment. A broader, whole-system, integrated approach to cSDH could bring benefit to patients, carers, and service providers.

The regional ‘hub and spoke’ model currently coordinating cSDH treatment [70] was identified in our discussions as a driver of many challenges, but it may also represent an opportunity for the development and implementation of solutions. First, many of the challenges pertaining to care *within* a region (such as inter-hospital transfer) may be common *between* regions, offering the opportunity to generate and share learning and best practice between referral networks. Methods such as collaborative multi-stakeholder consensus-building at scale may be especially helpful in enabling diverse expertise to be captured and synthesised into visions and delivery plans for “what good looks like” in areas including clinical pathways, case definitions, communication, and operational processes and work system design. This not only may aid in the rapid adoption of interventions such as best-practice statements or audit infrastructure in the short-term, but also creates a framework for comparing future complex interventions or research findings between centres, for instance in a cluster-randomised trial.

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# Conclusions and next steps

Chronic subdural haematoma is increasingly recognised as a ‘sentinel health event’[71,72].The multi-disciplinary ICENI collaborative has identified a number of challenges that must be addressed if the care of people with cSDH is to be improved. Many of these arise from distributed nature of care for the majority of these patients, leading to incomplete understanding of patient outcome, cross-speciality requirements, disease burden, and a supported decision-making process. The care improvements delivered in related clinical areas offer both a precedent for success, and potentially transferable solutions, although additional cSDH specific knowledge gaps remain. A wide-ranging programme of health services research is needed to tackle questions concerning models of care and service design, patients’ and families experiences of care and how best to share decisions, improvement strategies, and economic evaluation. [73–75]. Improving system design and processes will need to proceed hand-in-hand with a well-founded programme of research to address clinical questions, including those likely to benefit from randomised controlled trials. One uncertainty amenable to a trial, for example, is that of GA *versus* LA for cSDH, analogous to the GALA trial examining their use in carotid endarterectomy[76].

What is clear is addressing these challenges comprehensively will require a multi-disciplinary and system-wide approach. Similarly, we recognise that the challenges of implementing change will differ between healthcare systems, especially between high and low- and middle-income countries. Our next step is to identify key themes which could form the basis of working groups to address some of these challenges. These groups will seek to develop a consensus framework that could build towards a long-term goal of clinical practice guidelines. This process would be strengthened by further collaboration with any interested parties.

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**Figure Legends**

**Figure 1: Presenting symptoms of chronic subdural haematoma (cSDH)**. Percentages refer to the percentage of patients presenting with these symptoms in a nationwide audit of UK surgical practice[2].

**Figure 2: Comparison of patient pathways for chronic subdural haematoma and acute stroke demonstrating common themes and journeys.** Width of line indicative of proportion of patients in each diagnostic cohort following that pathway. Dashed lines indicate an ‘exceptional’ route of presentation (e.g. a patient with a chronic subdural transferred directly to a neurosciences centre as the closest local facility). Blue lines indicate pathway for patients with chronic subdural, Red lines indicate that for patients with acute stroke.

*AS = Ambulance Service, cSDH = chronic subdural haematoma, Dx = Diagnosis, IR = Interventional Radiology, Rx = Medical treatment, Sx = Surgical treatment.*

**Figure 3: The Knowledge to Action Cycle.** This demonstrates the cyclical nature of steps translating knowledge into action for a specific domain. This article seeks to identify problems and the ‘know/do’ gap in current care of chronic subdural haematoma (light box), the first step in any initiative to improve care. Figure adapted from *Straus* *et al 2009*[30]*.*

**Figure 4: Knowledge gaps in current care for chronic subdural haematoma (cSDH).** Red text indicates knowledge gaps identified by the ICENI collaborative. Green text at lower edge identifies four main steps that may be taken to advance care in this area. Percentages drawn from references [2,3]

**Table Legends**

**TABLE 1: Key requirements for improving the care of patients with chronic subdural haematoma derived from a meeting of national stakeholders.**

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# Funding

DJS is supported by a Wellcome Trust Clinician PhD Fellowship (Grant number: 220542/Z/20/Z)

BMD is supported an NIHR Clinical Doctoral Research Fellowship.

MDW is supported by THIS Institute’s grant from the Health Foundation. The Health Foundation is an independent charity committed to bringing about better health and health care for people in the UK. MD-W is an NIHR Senior Investigator (NF-SI-0617-10026).

PJAH is supported by the NIHR (Senior Investigator Award, Cambridge BRC) and the Royal College of Surgeons of England.

DKM is supported is supported by the NIHR through the Cambridge NIHR Biomedical Research Centre, and by a NIHR Senior Investigator Award

The Authors also wish to acknowledge the Cambridge NIHR Biomedical Research Centre (BRC) funding.

The views expressed in this article are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care.

# Acknowledgements:

This work has arisen from a Wellcome Trust funded Clinician PhD Fellowship (to DJS) and, being as the work was funded, in whole or in part, by the Wellcome Trust (Grant number: 220542/Z/20/Z) A CC BY or equivalent licence will be applied to any Author Accepted Manuscript (AAM) arising from this submission, in accordance with the grant’s open access conditions. The work was also supported by the Cambridge NIHR Biomedical Research Centre.

# Conflicts of Interest

WT has received speakers fees or sat on advisory boards for: Alexion, Portola, Sobi, Pfizer, Bayer, NovoNordisk, Ablynx, Daiichi Sankyo, Takeda and Sanofi.