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Editorial article

<u>Title: James Lind Alliance Priority Setting Partnerships Top 10 Research Priorities for</u> <u>Pancreatitis.</u>

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Introduction

Acute, recurrent acute and chronic pancreatitis can be separate illnesses; however, they can also represent a disease continuum. Pancreatitis can carry a heavy burden of symptoms and

complications that are debilitating for patients. In severe cases pancreatitis can be fatal (Gardner & Smith, 2017).

Problems in UK clinical care for pancreatitis were first highlighted almost a decade ago. In 2014, a National Confidential Enquiry into Patient Outcome and Death (NCEPOD) for pancreatitis was commissioned on behalf of NHS England. The enquiry found efforts to identify and manage the cause of acute pancreatitis were inadequate and access to specialist services was inequitable. The establishment of formal regional tertiary networks was recommended. So that all patients can access specialist opinion and interventions for complex pancreatitis, regardless of which hospital they present to (O'Reilly et al., 2016). In 2018 the National Institute for Health and Care Excellence (NICE) guidelines echoed the NCEPOD report, agreeing specialist regional 'hub and spoke' networking with an MDT approach to management and support is required for pancreatitis (NICE, 2020). A list of regional pancreatic centres can be found on the Pancreatic Society of Great Britain and Ireland (PSGBI) website (PSGBI, n.d) at www.psgbi.org/patient-information/specialist-centres/

Despite ongoing improvements in the way UK pancreatitis care is organised and delivered, providing evidence-based care presents significant challenges. This can be attributed to limited healthcare resources, but also because pancreatitis is an under researched area. Much is unknown in the management of pancreatitis and patient involvement in pancreatitis research in the UK has previously been lacking (Mitra et al., 2023). However, recent national strategic work performed in partnership between healthcare practitioners, patients, and the James Lind Alliance (JLA) aims to improve this situation going forward.

Here, we discuss the impact pancreatitis has on patients and introduce the JLA top 10 pancreatitis research priorities. Suggestions on how nurses can support improvements in pancreatitis care are also proposed.

Pancreatitis

The pancreas is a digestive organ that lies near to the stomach, small intestine, gallbladder, and liver. It has two main important functions. Firstly, the production of enzymes to digest food (exocrine function) and secondly, the pancreas produces hormones such as insulin to control blood sugar levels (endocrine function) (Rizzo, 2016). Pancreatitis is inflammation of the pancreas.

Acute pancreatitis accounts for 20,000 UK hospital admissions per year. This is mainly caused by gallstones or excessive alcohol. However, there are other causes including metabolic conditions, hereditary genetic mutations, as well as autoimmune disease (Roberts et al., 2013). Symptoms include abdominal pain, nausea, and vomiting. A local and systemic inflammatory response syndrome (SIRS) occurs. For most individuals it is a mild illness requiring a few days of hospital treatment. However, around 20% will develop moderate or severe pancreatitis, with necrosis of the pancreas tissue and multi- organ failure (Van Dijk et al., 2017). Patients with severe acute pancreatitis require admission to critical care for organ support. There is a high mortality rate of one in four in this group (Portelli & Jones, 2017).

Chronic pancreatitis occurs when prolonged inflammation leads to fibrosis and calcification of the pancreas. Diagnosis can be challenging and is usually made in advanced stages (Duggan et al., 2016). There are 12,000 hospital admissions annually in the UK (Hall et al., 2014). Prolonged excessive alcohol consumption is the most common cause (Gupte et al., 2018). Smoking tobacco is a risk factor. Chronic disease can also follow episodes of severe acute and recurrent acute pancreatitis (Whitcomb, 2019). Symptoms include chronic abdominal pain that radiates to the back, nausea, vomiting, steatorrhea (greasy loose stools), weight loss and fatigue (Forsmark & Pham, 2018). Common complications include impairment of pancreatic function known as type 3c diabetes and pancreatic exocrine insufficiency resulting in malnutrition. There is also an increased risk of pancreatic cancer (Majumder & Chari, 2016). The mortality rate is almost 50% within 25 years of disease onset (Braganza et al., 2011).

Severe complications can arise in both acute and chronic pancreatitis. These can be multisystemic resulting in obstruction of the gastrointestinal tract and biliary system. Thoracic and abdominal fluid collections (including pseudocysts) can feature in both these diseases. The vascular system can be affected by portal and splenic vein thrombosis, which may lead to portal hypertension and the development of oesophageal and gastric varices with haemorrhage (Roberts et al., 2017; Majumder & Chari, 2016).

There are no curative treatments for pancreatitis (Duggan et al, 2016). Current practice focuses on measures to prevent repeated attacks or disease progression and the supportive treatment of symptoms and complications (Majumder & Chari, 2016). In acute pancreatitis treatment includes goal directed fluid resuscitation (Van Dijk et al., 2017). In both acute and chronic pancreatitis, pain is treated using a range of pharmacology with an awareness of addiction. Pancreatic enzyme replacement therapy, nutritional support and adjustment of diabetic agents may be required. Selected patients need specialist endoscopic, radiological, and surgical interventions to manage complications (NICE, 2022). Lifelong surveillance for complications is required in chronic pancreatitis. Psychological support is also needed, but often overlooked (Gupte et al., 2018).

The impact of pancreatitis for patients

Pancreatitis can be devastating for patients and their families. Following acute pancreatitis, patients report feelings of stress, anxiety and fear, and some struggle to recover and return to normal life quickly (Boije et al., 2019). For those living with the ongoing symptoms and complications of chronic pancreatitis, there can be a heavy burden. Physical disability, substance dependence, anxiety, depression, social isolation, and reduced quality of life are common. There is also an economic effect, as patients may be unable to work (Cronin & Begley, 2013). Additionally, there is stigma associated with pancreatitis. Patients often feel judged and perceive a lack of understanding from friends, relatives, health-care professionals, and employers (Mitra et al, 2020).

Guts UK Charity recognised public awareness about pancreatitis requires improvement and launched their Kranky Panky Campaign in 2018 (Figures, 1,2,3 & 4). The campaign runs throughout the month of November annually. A patient story is shared every day of the entire month through the charity's website and social media platforms. The stories provide a powerful insight into patient experiences. However,



published research exploring the experiences of pancreatitis patients is sparse and there are large knowledge gaps in many areas of clinical understanding of the disease.

James Lind Alliance Priority Setting Partnership









In 2021, a James Lind Alliance (JLA) priority setting partnership (PSP) was formed for pancreatitis. The PSP was co-funded by Guts UK Charity, British Society of Gastroenterology (BSG) and Pancreatic Society of Great Britain and Ireland (PSGBI). The aim of the PSP was to identify the top ten uncertainties in pancreatitis, answerable by research. The JLA PSP methodology is recognised by the National Institute for Health Research (NIHR) as a collaborative way to identify and define research uncertainties (NIHR, 2022). The involvement of both patients and healthcare professionals in the PSP process helps direct future research, widening the scope into key areas that are important to the people affected by the disease (JLA, 2022b; Boivin et al, 2014).

A diverse steering group was established with equal representation from health care professionals, pancreatitis patients and their carers. The group developed a protocol and agreed the scope of the PSP would cover the causes, diagnosis, treatment, management, and support for pancreatitis. A UK wide survey was circulated through different professional organisations and charities to ask what pancreatitis questions should be answered by research. Responses were received from a range of health care professionals, patients, and carers. The steering group processed all questions posed. Questions outside of the scope and duplicates were removed. A trained researcher then performed an evidence check to ensure the questions had not already been answered by research. This generated a list of 55 unanswered questions. Two final surveys (one for adults and one for young people 11+) were then distributed. People were asked to choose their top 10 questions out of the 55. The top 23 questions that secured the most votes were then taken to a final steering group workshop. Here the group ranked the questions in three rounds to agree on the top 10 research priorities for pancreatitis (Figure 5 & 6).

Figure 5. The JLA process (Guts UK Charity, 2022)

Figure 6. The Top 10 (JLA, 2022a)

The top ten research priorities for pancreatitis cover a range of themes. The priorities can help interested researchers focus their research efforts in key areas and attract different funding bodies to support grant applications (Mitra et al, 2023).

Nurses can support improvements in care for pancreatitis by having awareness of the difficult symptoms, complications, and stigma patients with pancreatitis experience. Signposting to resources like those available from Guts UK Charity can help inform and support patients- <u>www.gutscharity.org.uk/advice-and-information/conditions/</u>. Nurses working in services caring for pancreatitis patients can use embedded NHS quality improvement methods to evaluate and improve their local services to meet the needs of local patients. Joining nursing forums through professional organisations like the BSG and the PSGBI will provide education, training and guidance on pancreatitis and research activities. Finally, nurses interested in research can contribute to the evidence by aligning their research projects to address priorities listed in the top ten. This would reduce the burden of the illness, improve symptoms and overall health and wellbeing for patients with pancreatitis.

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Figure 1

Steve's story



"My husband died in March 2020 after spending 3 months in intensive care with severe **acute pancreatitis** (SAP), so I have first hand experience of the effects of this terrible disease. Within 48 hours of being diagnosed he started suffering multiple organ failure. It was beyond heartbreaking to witness. Sadly, this is common in patients with SAP, drastically reducing their chances of survival. Being able to prevent and actively treat organ failure will significantly improve the outcome of patients with SAP." David, remembering his husband Steve Figure (i.e. diagram, illustration, photo)

Click here to access/download;Figure (i.e. diagram, illustration, ≛ photo);Figure 2.docx

Figure 2

Katen's story



"It would mean a lot to find ways in preventing pancreatitis becoming worse. It could open me up to being able to eat properly, without having to worry about everything I eat. It could put my mind at rest. Continued research would give hope that pancreatitis is eradicated sooner rather than later, potentially improving my quality of life. I'd feel better overall, knowing there are wider options out there to help pancreatitis sufferers further."

Katen

Mandy's story

"I left hospital after my first attack without any information or advice. I was given no information on diet or lifestyle changes. No one explained malnutrition to me, that it could cause weight and hair loss. Even after my worst attack and five-month-stay in hospital, I left for home with no follow-up plan, no information or advice. I also left with no knowledge of what had happened to me and my body, during those five months in hospital.

I want to see more support, advice and information, so people don't feel 'turfed' out of hospital, left to struggle on their own. I want to see people have the information that I never had." Mandy



Zaki and Talia's story

"Both our children have genetic mutations that place them at higher risk of pancreatitis. Day-to-day we live with the anxiety of never knowing when another acute attack might occur. Seeing our children suffer and knowing there are very few treatment options available is heartbreaking. We are hopeful that research into gene therapy might find a way to treat or even cure those with genetic pancreatitis. This would mean our children could lead healthy and happier lives without the need for frequent hospital stays or medical interventions." Claire and Mohamed, parents of Zaki and Talia







Pancreatitis Top 10

- 1. Are there better ways to treat and manage acute and long-term pancreatitis pain, for example using non-opioid (painkillers) drugs?
- 2. What can be done to prevent pancreatitis becoming worse, and to stop or reverse the damage to the pancreas?
- 3. Are there better ways to reduce inflammation in people with pancreatitis, both in the pancreas and the rest of the body?
- 4. How can pancreatitis be diagnosed more quickly and accurately, especially on admission to hospital?
- 5. How can people with pancreatitis be helped to manage their condition post-diagnosis (after being diagnosed) e.g. by giving information about diet, medication and lifestyle changes?
- 6. Are there better ways to treat and manage flare-ups (when symptoms get worse) in people with chronic pancreatitis?
- 7. Can gene therapy (altering genes inside the body's cells) be used to treat people with pancreatitis?
- 8. How can multiple organ failure be prevented in those people with pancreatitis who become seriously ill? How can the care of those people with multiple organ failure be improved?
- 9. How can pancreatic cancer be diagnosed earlier in people with pancreatitis?
- 10. What are the psychological (mental and emotional) impacts of pancreatitis? What are the best ways to treat and support people (both young people and adults) with pancreatitis who experience mental health problems?