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Why is priority setting important for global burn care research?

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Abstract

The use of robust evidence is a key component of providing high quality care to patients. Synthesised evidence to support clinical decision-making is lacking for many aspects of clinical burn care. Identifying the most important areas of care that lack high quality evidence and requires research is necessary, as funding for primary research is limited. Priority setting research studies are a joint endeavour between patients, carers and clinicians to identify and rank topics for research in a healthcare area in order to reduce research waste. Such an exercise has yet to be undertaken in burns. The aim of this paper is to outline the importance of research prioritisation in burn care, to discuss how it facilitates the maximum benefit from limited research funding and to explain the methodologies used.

Highlights

- Research priority setting has not yet been undertaken in burn care.
- There is a lack of clarity regarding the gaps in evidence for burn care
- There is limited funding for multiple trials needed to provide evidence
- Prioritising research topics in burn care will maximise investment impact.
- Involving international burn survivors and clinicians will ensure relevance.

Background: Burn injuries are common, affecting 11 million people worldwide annually(1). While most patients survive, many experience long-lasting functional, psychological and cosmetic morbidity(2, 3). Population studies link burns with increased risks of cancer, cardiovascular disease, diabetes, and depression(4). Healthcare costs are substantial due to multiple surgeries, long hospital stays, and psychological and physical rehabilitation(5). Despite this, there is a mis-match between disease burden and volume of synthesised patient-relevant evidence, and a lack of understanding of the importance of focusing research on evidence gaps(6, 7).

The reasons for the lack of synthesised evidence providing the answers to questions important to patients with burns are multi-factorial. Randomised controlled trials (RCTs) in burn care are commonly small, single site, and of poor quality(8, 9). Synthesis is difficult as multiple different outcomes are reported at different times after injury(8). Importantly, burn research also lacks prioritisation to areas of evidence uncertainty, and patient need(10). This matters, because single-question RCTs are costly and there is a scarcity of funding available for multiple trials. (11, 12). In the UK, health research funding of £4.8 billion was invested in 2018(13). The largest funding increase was for infectious diseases and cancer research. Research into 'skin', and 'injuries and accidents', together, received only 1.2% of the total UK healthcare research budget. A report by Rottingen and colleagues, showed that funding for global health research in 2009 was US\$240 billion(14). The report demonstrated that there were substantially more research gaps in health research for diseases prevalent in lower income countries; this includes burns(15).

The impact of an inability to fund multiple large multicentre RCTs in burn care limits synthesised evidence. New techniques will therefore be introduced without scientific evaluation, with the potential to cause harm(16). Treatment is therefore driven by clinician preference and habit, leading to variation in practice, with some patients experiencing suboptimal recovery(17, 18). This variation needs to be reduced through production of evidence achieved through research focused on areas of clinical need with a verified lack of evidence. Aligning areas of clinical need with the views of burn care stakeholders is a global challenge(14). Research waste occurs when the views of stakeholders (specifically patients, carers and clinicians) are ignored and existing evidence is overlooked(19-21). Prioritising the

most important areas for research ensures an effective use of research funding maximising the impact of investment(19, 22). To date, no evidence gap analysis or prioritisation exercise has been conducted in burn care. The aim of this paper is to outline the considerations, impact and logistics of implementing a global priority setting partnership in burn care.

Priority setting methodology: Research selected through a priority setting study aims to achieve consensus on clinical questions of most importance to stakeholders and without evidence (23, 24). Study design for prioritising health research is still evolving and various approaches exist, with no agreement on best practice. It is vital that the methodology should be explicit and reproducible. In 2010, Viergever and colleagues undertook a literature review of health research priority setting studies coordinated by the World Health Organization. The authors proposed nine good practice guidelines for such studies(7). These allow for different methodology in different settings. In 2019, the “REporting guideline for PRiority-SEtting of health research” (REPRISE) guideline was published(25) . The guideline contains 31 reporting considerations in ten domains, including funding, context and impact.

The James Lind Alliance ((<https://www.jla.nihr.ac.uk/>) (JLA)), represents the most commonly used methodology. The JLA is a UK healthcare priority setting partnership, supported by the National Institute for Health Research (NIHR). More than 100 priority setting partnerships (‘PSP’s’) have so far been established in a variety of clinical fields(26-28). Through this process, patients, carers and clinicians work together to identify and prioritise clinical uncertainties (29). The methodology is described in Table 1 and in the JLA handbook(30). Research has shown that agreement between patients, carers and healthcare staff on areas of research that are important, differ, and that both must be taken into account(31-33) . It is important to the organisation that the patient voice is strong(30, 34, 35). Therefore both patients and professionals are involved in the steering group and rank the long list of candidate research priorities for importance. The JLA does not advise on involving international stakeholders. Many PSPs are undertaken on a national basis. Undertaking a priority setting globally makes sense when the burden of disease or injury is global in nature(36, 37). This is true for burn injury(38) .

Study phase	Process
1	Establish a steering group to set the scope and agree methodology. Involves patients and clinicians.
2	Identify and engage with stakeholders.
3	Formulate an initial long-list of clinical uncertainties through a survey and stakeholder interviews.
4	Collate the clinical uncertainties into 'in scope' research priorities, and verify that these lack evidence.
5	Shortlist the priorities through a second survey.
6	Agree the top ten priorities through a consensus meeting.
7	Work to develop research questions in the 'population, intervention, comparator and outcome' (PICO) style based on the agreed priority areas.

Table 1: JLA methodology phases

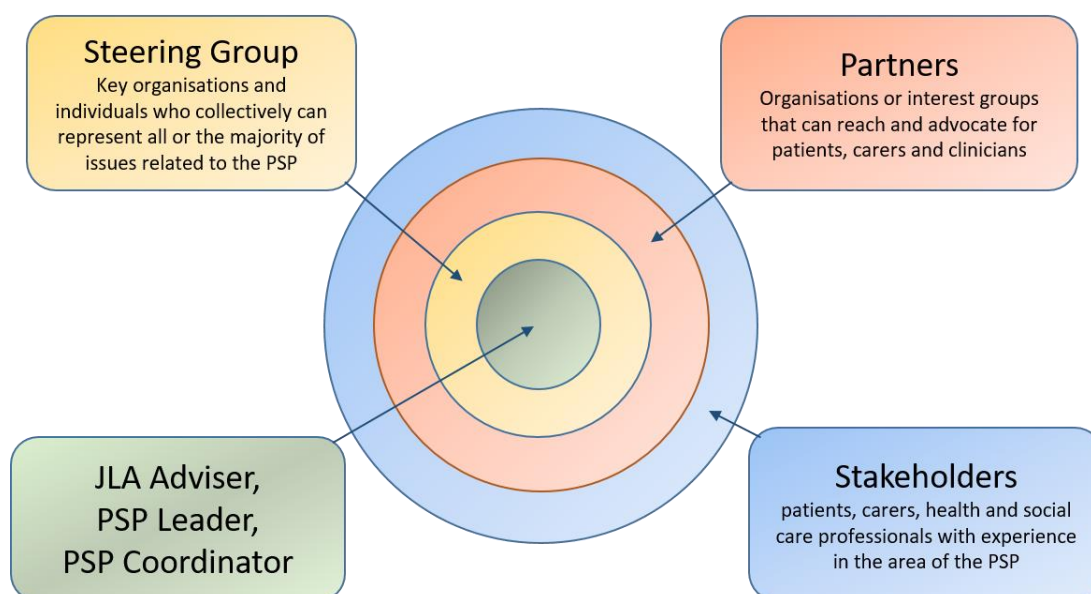


Figure 1: JLA organisational structure (with permission from the James Lind Alliance(27).)

Other methods for research priority setting exist. Examples include: the Child Health and Nutrition Research Initiative (CHNRI) initially formed to address global child health issues(39, 40), the Council on Health Research for Development (COHRED)(41), and the 'Dialogue Model' framework (42). All methodologies have a survey-based investigation to identify

potential priorities, methods for verifying that the questions have no synthesised evidence, involve stakeholder involvement for ranking the priorities and have a final workshop or meeting. Prioritised questions are usually broad areas for research, for which specific questions will later be proposed(43).

Priority setting in global burn care: Research is lacking in many areas of burn care for reasons described above. Other reasons include the multidisciplinary nature of burn care and the varying systemic nature of the injury. Large area and deeper burns impact patients' immunology, metabolism and homeostasis, producing a whole body insult. Beyond the initial trauma, the patient may suffer from psychological morbidity and issues with long-term function, through scarring. Psychological morbidity occurs independently of the severity of the burn(44).

There is a large body of clinical and translational burn care research that directly and indirectly impact patients' care. Several areas have well established practice through evidence. Examples include the use of early tangential excision(45), the management of hypermetabolism(46) and early fluid resuscitation(47). Nevertheless, several areas of practice have clear evidence gaps. These include, but are not limited to, the choice of wound dressings, diagnosis and management of wound infection and proactive management of psychological well-being. These are clinician-identified priorities. They may differ from the perspective of the patient. The patient may, for example, prioritise psychological rehabilitation, and return to daily living as areas for research. Post burn hypertrophic scarring and its sequelae continue to be one of the greatest unmet challenges following injury of concern to both patients and clinicians alike(48).

A further complexity with burn care, is that the majority of injuries occur in lower middle income countries (LMICs)(1). Most burns research, however, is conducted in higher income countries (HICS). Agreeing the focus of global collective research efforts is an important challenge that requires a partnership between low and high income country international multidisciplinary burn clinicians and their patients.

Recently, a project has been started in the UK to prioritise areas for research into global burn care. The most international steering group in the history of the JLA, led by the University of Bristol and in partnership with the National Institute for Health Research and James Lind Alliance, have undertaken to develop a global priority setting partnership for burn care. The methodology for this project is described in detail in this issue of Burns. The aim of the study is to identify using JLA methodology the top ten priorities for research in global burn care through questionnaire surveys, interviews and workshops with international patients and healthcare teams. These priorities will guide governments, research funders and clinician scientists to focus research funding in areas without evidence that are important to all stakeholders, thus decreasing irrelevant and wasteful research.

Dissemination and impact: The aim of the global burns PSP is to generate a list of 10 key focus areas for research. These will be disseminated through publications in high impact journals, presentations at meetings, social media and through relevant national research bodies. Work to turn the priority areas into research questions will ensure impact (49). The prioritisation list will feed into the NIHR and other UKRI funders, to inform their decision making for research funding. Currently the NIHR has a rolling call through four participating funding streams for research projects based on agreed JLA priority areas.

Whilst the concept of prioritising research fields may appear to be a streamlining process that may threaten individual interests, it in fact does the opposite. It allows a fresh perspective on how the priorities fit into burn care. It provides evidence to funders, of the importance and scale of burns as a healthcare problem. It also provides burns clinician scientists with increased potential to secure research grants to provide evidence for the most important unanswered questions. It is hoped that this prioritisation exercise will stimulate debate amongst the international burn community and generate engagement between patients and clinicians across the world to focus the global burn research agenda for the medium term.

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