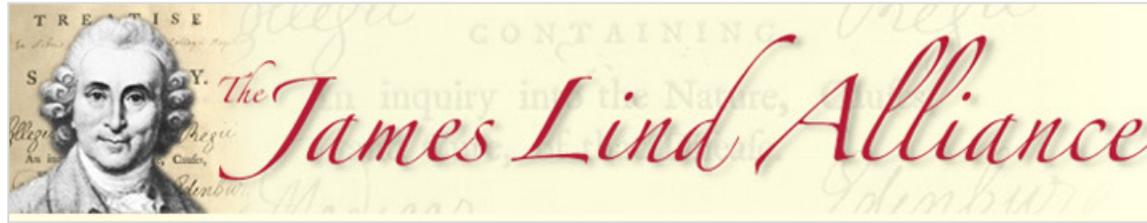# Stakeholder involvement in developing priorities for UK intensive care research

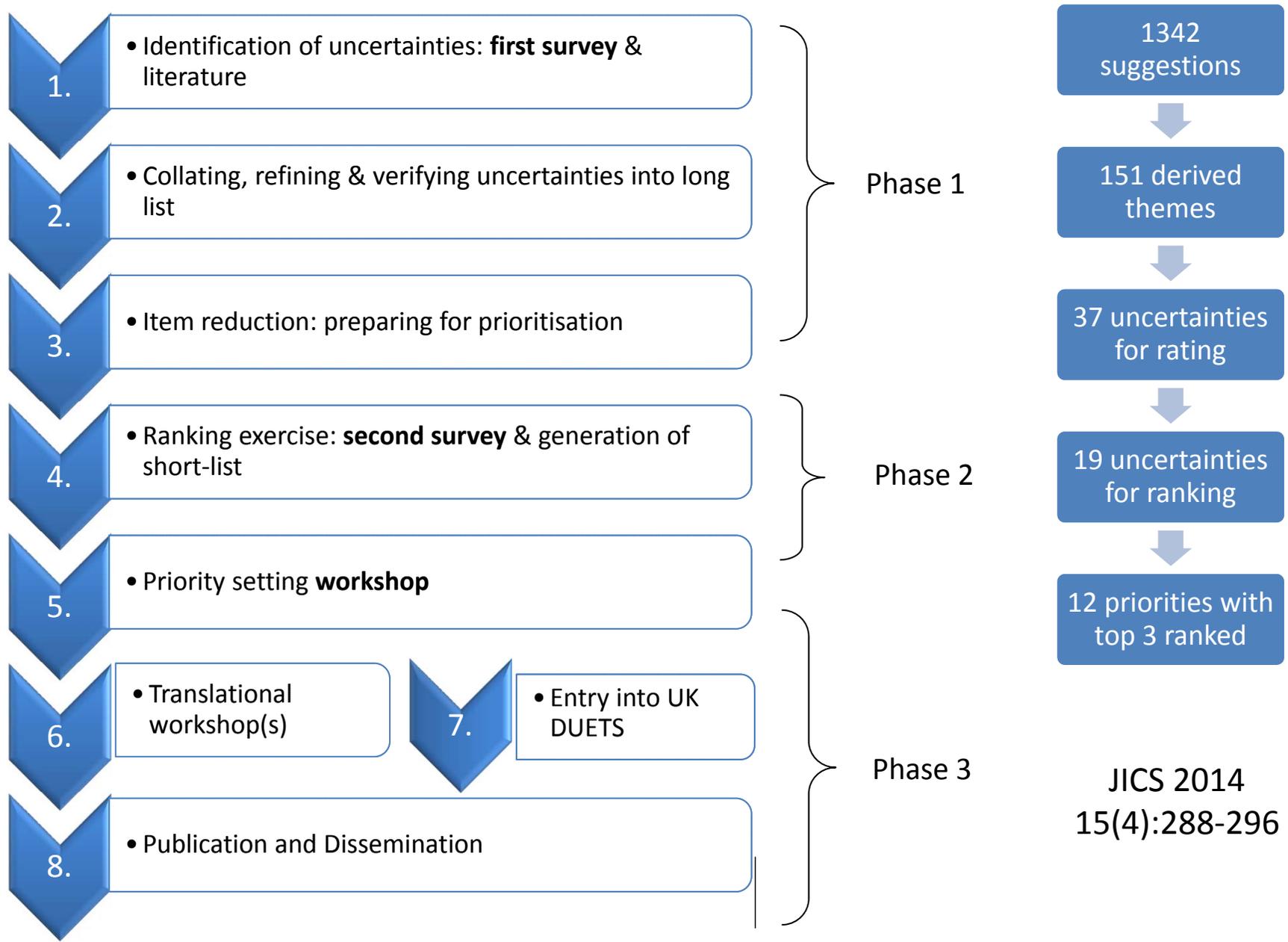*(...insights & lessons learnt!)*

What is the James Lind Alliance?

- Non-profit making initiative, established in 2004

- Now part of NIHR

- It brings patients, carers and clinicians together in research Priority Setting Partnerships (PSPs)

- These Partnerships identify and prioritise uncertainties, or 'unanswered questions', about treatments that they agree are the most important.

    = Well-established, **structured** and **transparent** research prioritisation process

    = **Influential** for research funders

JLA Priority Setting Partnerships

• Asthma	• Dialysis (Canada)
• Urinary incontinence	• Dementia
• Vitiligo	• Hip and Knee replacements
• Prostate cancer	• Lyme disease
• Schizophrenia	• Pre-term birth
• Type 1 diabetes	• Hidradenitis suppurativa
• ENT aspects of balance	• Inflammatory Bowel Disease
• Stroke	• Acne
• Eczema	• Childhood disability
• Sight loss and vision	• Neuro-oncology
• Tinnitus	• *Anaesthesia & perioperative care*
• MS	• *Kidney transplant*
• Pressure ulcers	• *Palliative & end of life care*
• Parkinson's Disease	• *Surgery for shoulder problems*

1. • Identification of uncertainties: **first survey** & literature

2. • Collating, refining & verifying uncertainties into long list

3. • Item reduction: preparing for prioritisation

Phase 1

4. • Ranking exercise: **second survey** & generation of short-list

5. • Priority setting **workshop**

Phase 2

6. • Translational workshop(s)

7. • Entry into UK DUETS

8. • Publication and Dissemination

Phase 3

1342 suggestions

151 derived themes

37 uncertainties for rating

19 uncertainties for ranking

12 priorities with top 3 ranked
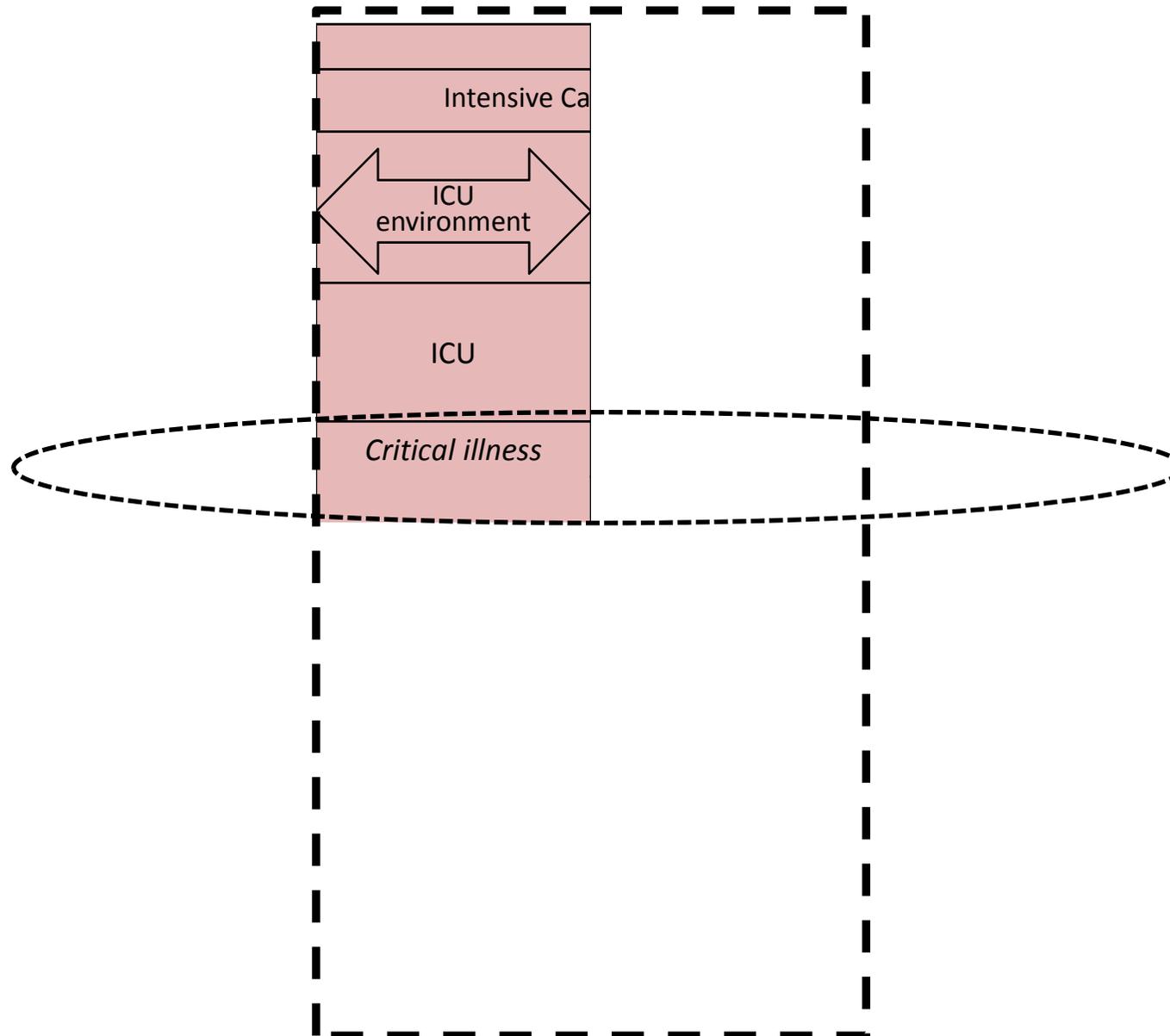
JICS 2014
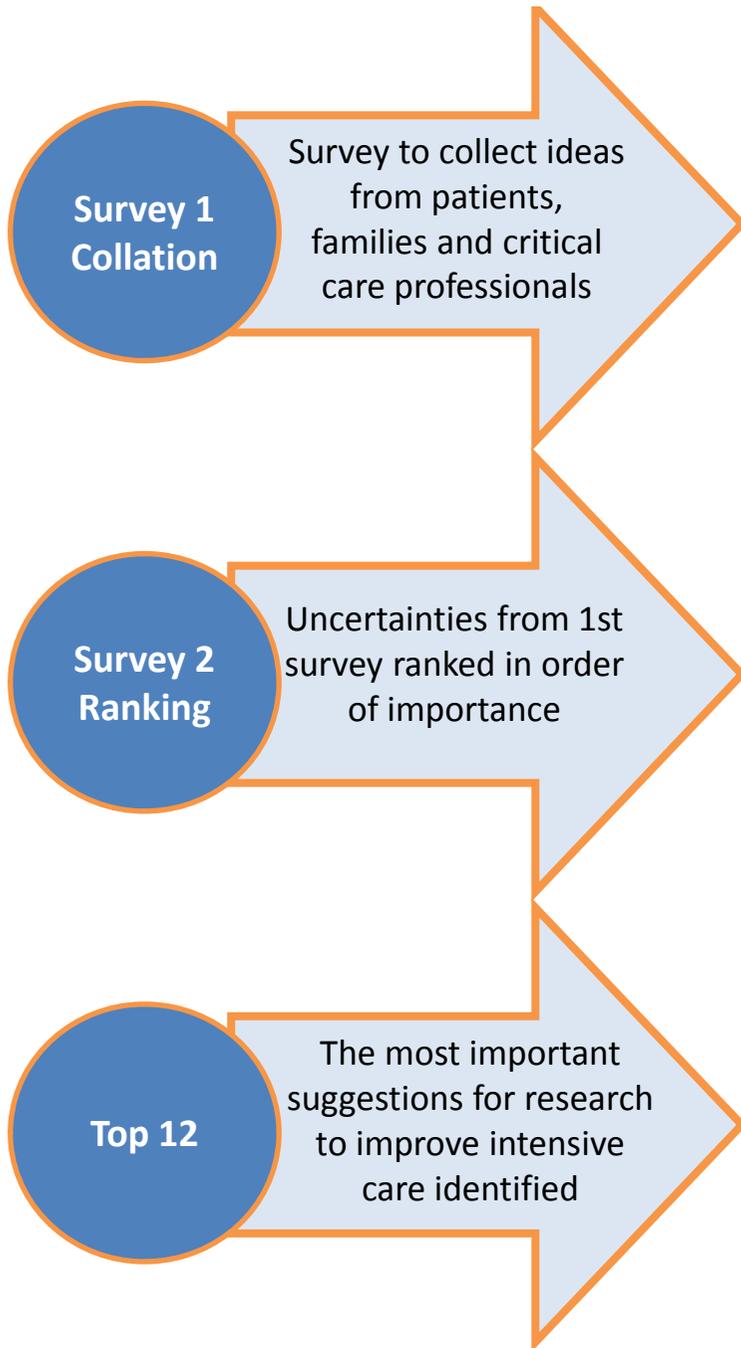15(4):288-296

Challenges of engaging patients and families

- Identifying our PPI population – scope of project

- Clarity of the task

- Research awareness

- Using these unique insights – answering the "so what…?"
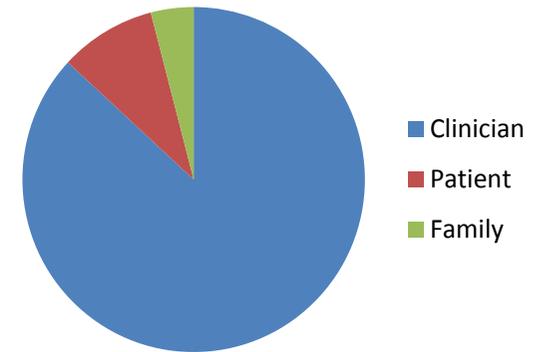
question

Identifying patients & families: Scope
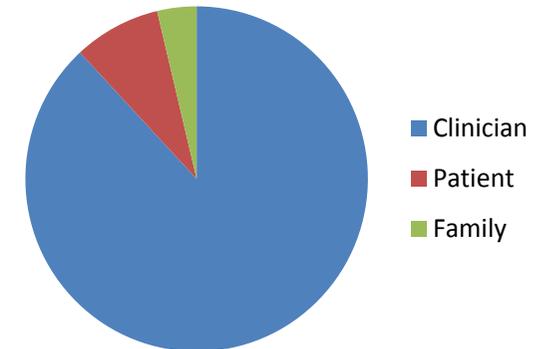
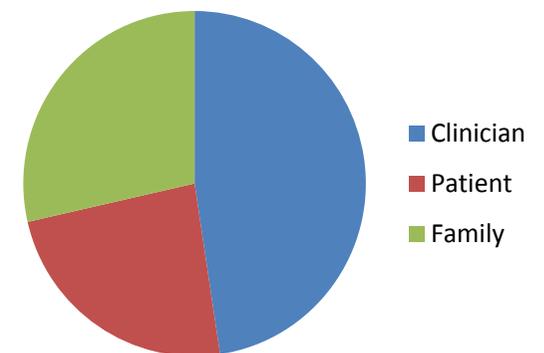# Identifying patients & families: Scope

Survey 1 Collation — Survey to collect ideas from patients, families and critical care professionals
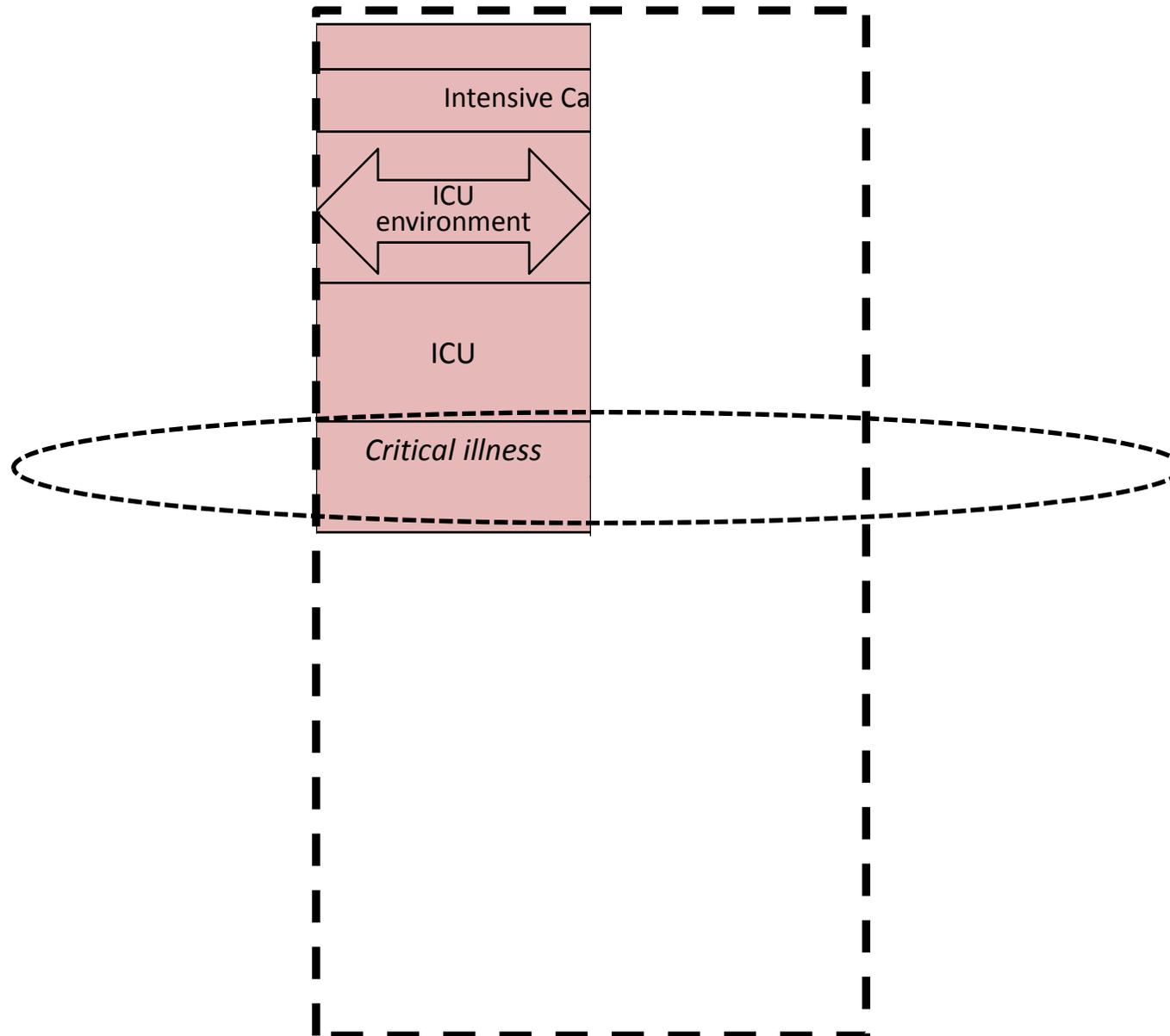
146 UK ICUs (PICs)
484 participants
>1200 suggestions

Clinician
Patient
Family

Survey 2 Ranking — Uncertainties from 1st survey ranked in order of importance

146 UK ICUs
≥ 513 respondents

Clinician
Patient
Family

Top 12 — The most important suggestions for research to improve intensive care identified

21 NG participants

Clinician
Patient
Family

Imperial College London

The James Lind Alliance

intensive care foundation
science saving life

Clarity of the task!

What questions about the treatments for [health problem] would you like to see answered by research?

"What do we need to find out about treating people in intensive care to promote survival and improve life during or after intensive care?"

"Need more information on the long term sequelae, especially in those with significant co-morbidities" (P651)

"…their medical history" (F174)

.**"…why they are sitting in front of you"** (P575)

"What are the specific consequences or prognoses resulting from particular treatment strategies" (P949)
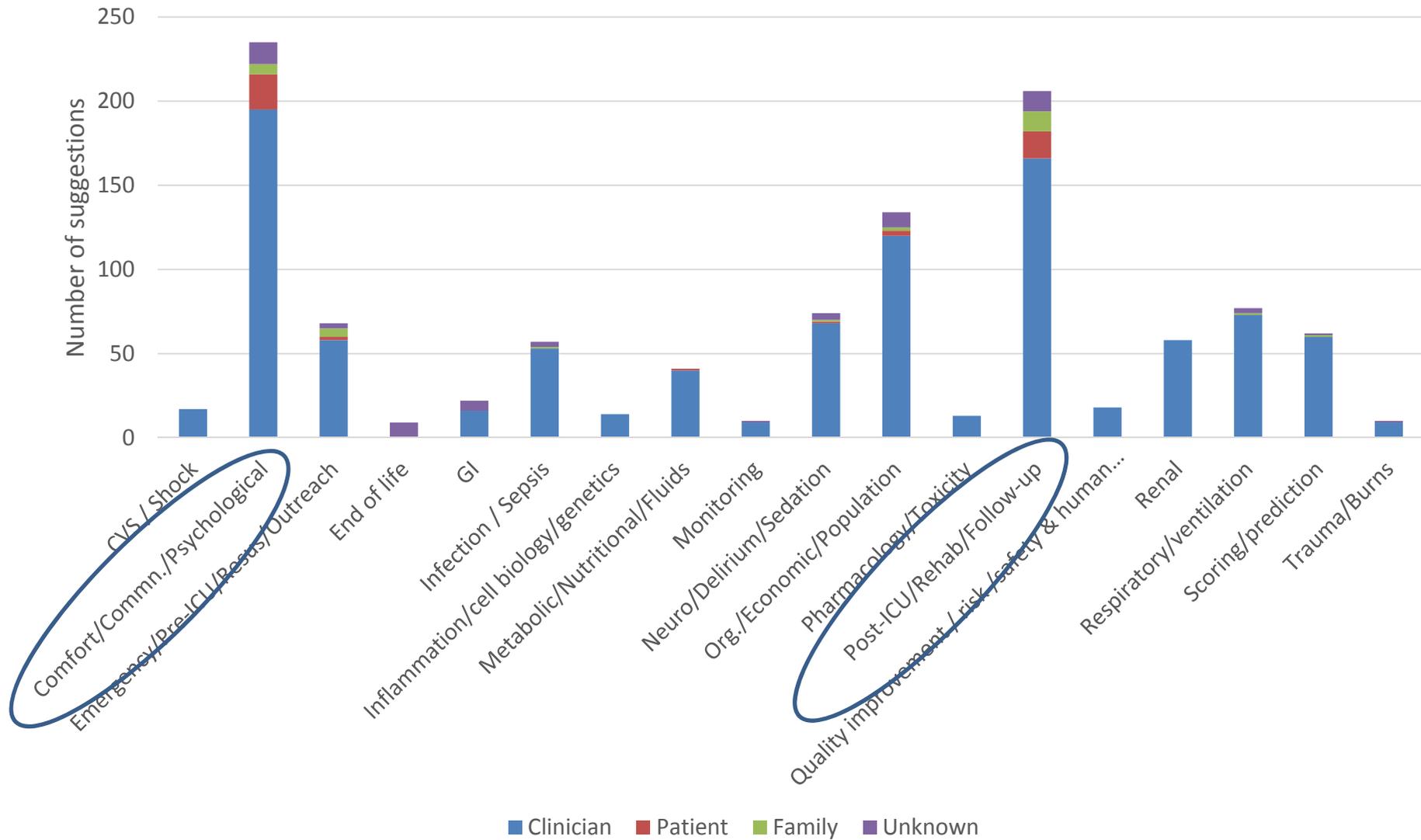
"How does the impact of someone in ICU affect the relative during the ICU stay and after discharge" (P38)

"…likes / interests e.g. TV, type of music etc." (C295)

"…a person's personality – anxious, laissez-faire, easily upset etc." (C516)

"How to prevent muscle wastage…as this affects mobility and causes general weakness in the months after return home" (F152)

"…if they wear glasses, give them back as soon as you can. Otherwise they might think they are on a spaceship not in ICU." (P713)

How to limit the number of infections a patient has during their time in intensive care" (F113)

Generating research topics

Chart showing "Number of suggestions" (y-axis, 0 to 250) by research topic category, with stacked bars colored by source: Clinician (blue), Patient (red), Family (green), Unknown (purple).

Categories (x-axis): CVS / Shock, Comfort/Commn./Psychological, Emergency/Pre-ICU/Resus/Outreach, End of life, GI, Infection / Sepsis, Inflammation/cell biology/genetics, Metabolic/Nutritional/Fluids, Monitoring, Neuro/Delirium/Sedation, Org./Economic/Population, Pharmacology/Toxicity, Post-ICU/Rehab/Follow-up, Quality improvement / risk /safety & human..., Renal, Respiratory/ventilation, Scoring/prediction, Trauma/Burns

Legend: ■ Clinician ■ Patient ■ Family ■ Unknown

Rating & Ranking Topics

- Majority of topics were prioritised by patients and families, even if the topics were not originally proposed by this group (34 out of 37 topics had mode score of 10)

- Almost no discriminatory value of rating by patients/families prior to workshop

BUT

- Assurance that topics relevant to patients and families once identified

"…don't know what you don't know"

- Support for the highest ranked suggestions from all stakeholder groups in NG

Research Priorities

1. How can patients who may benefit from intensive care be identified early and admitted to the ICU at the right time?

2. How can patients and their families be best supported as they start living at home again (e.g. health & social care services, ICU support groups, long term follow-up)?

3. What is the best way to identify patients with or at risk of delirium or agitation – how should the immediate and long term effects of delirium or agitation be monitored or managed?

HAI	**Psychological support**	**Using pt/relatives experiences**
Rehabilitation	**Predicting who will benefit**	**Preventing lung damage**
Patient comfort	**Knowledge-Practice**	**Iatrogenic physical disability**

Research Awareness

- Pre-requisite knowledge depends on the task & context of involvement

- Lay involvement in development of surveys, information sheets and wording at all stages

- Prioritised topics broad enough to encompass a range of questions and associated methodologies

- Sources of support…
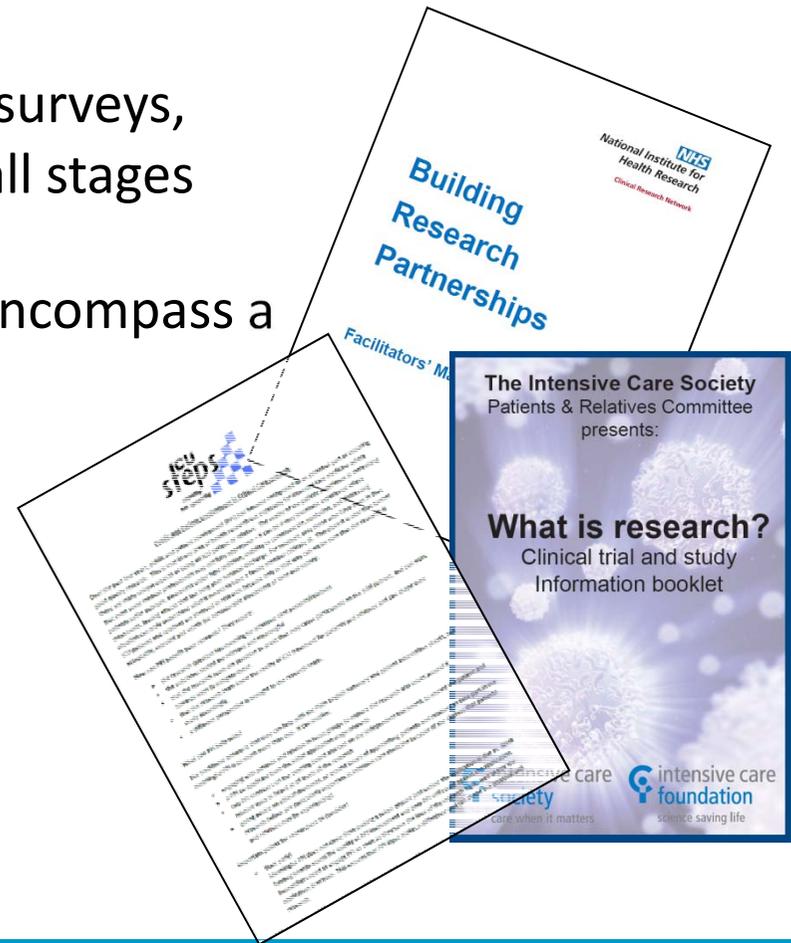
"PPI...so what...?"

I would like to see research into the long term effects of ICU delirium. I don't mean months after but years. I'm still suffering after 12 years" (P136)

"Need to understand more about the effects of drugs on patients...by far the worst experience for me was due to the effects of the sedation and the hallucinatory experiences on ICU" (P543)

We need to find a kinder way to ventilate patients. Being on a ventilator is the very worst thing ever" (P546)

"...I found cards and letters...were a great source of courage and strength to me. Gifts...were highly appreciated by my wife – I don't mean valuable ones, but receiving a shepherds pie...was a great help when my wife and children were spending most of their waking hours at my bedside...Two friends managed the regular bulletins on my state of health and handled emails on the subject so my wife was not under further pressure to deal with them and phone calls. I could give a lot more practical hints! (P536)

Next Steps

- Translation of uncertainties into research questions

- Funding and support for high quality research to address these prioritised uncertainties

Acknowledgments

The JLA Intensive Care PSP gratefully acknowledges the support and contribution of all participating ICUs, and the staff, patients and families who participated in this project. In particular:

Imperial College London

The James Lind Alliance

intensive care foundation
science saving life