

# Partnering with Survivors & Families to Determine Research Priorities for Adult Out-of-Hospital Cardiac Arrest: A James Lind Alliance Priority Setting Partnership

<https://doi.org/10.1016/j.resplu.2021.100148>

## For which topic were research priorities identified?

adult out-of-hospital cardiac arrest

## In which location was the research priority setting conducted?

North America - Canada

## Why was it conducted at all?

Research priority setting in health care has historically been done by expert health care providers and researchers and has not involved patients, family or the public. Survivors & family members have been particularly absent from this process in the field of resuscitation research and specifically adult out of hospital cardiac arrest (OHCA). However, survivors and family members have been particularly absent from this process in the field of resuscitation research.

## What was the objective?

to identify research priorities in adult out-of-hospital cardiac arrest from all perspectives, in particular examining where priorities converged and diverged between different stakeholders so that a robust research agenda that speaks to everyone impacted by OHCA can be built

## What was the outcome?

a ranking list of 10 research questions

## How long did the research prioritization take?

September 2018 - January 2020

## Which methods were used to identify research priorities?

JLA method

## How were the priorities for research identified exactly?

Step 1: identifying uncertainties: online survey with four open-ended questions to prompt people to think through the trajectory of an out-of-hospital cardiac arrest from the incident to hospital discharge or death, total of 1500 questions submitted. Step 2: refining questions and uncertainties: out-of-scope and unclear submissions removed, 556 out of scope questions removed, 944 in-scope responses assigned to eight categories reflecting broad themes, questions formatted into PICO format, 75 indicative questions formulated, long list of research uncertainties checked against evidence, resulting in 67 questions. Step 3: interim ranking: online survey with remaining long list of uncertainties, participants asked to identify the ten most important questions from their perspective from within the longer list, top 5 for each respondent group (patients & families, lay responders, health professionals, and EMS providers) were selected. Step 4: final prioritization workshop: participants were asked to individually reflect on and rank the research questions in order of priority from 1 to 20 and to bring their rankings to the workshop, during workshop small group deliberations and rankings

## Which stakeholders took part?

Persons who have survived cardiac arrest, spouse/ relative/ friend/ caregivers of someone who survived a cardiac arrest, spouse/ relative/ friend/ caregivers of someone who did not survive a cardiac arrest, healthcare professional: physicians, nurses, rehabilitation specialists, paramedic/EMS providers, dentists, optometrists, others. Survey: 408 participants. Interim ranking: 314 participants. Workshop: 20 participants: 5 survivors, 5 family members, 1 lay responder, 3 emergency department physicians, 2 critical care nurses, 2 paramedics, 1 CPR trainer, and 1 cardiac rehab specialist), and 3 independent facilitators.

## How were stakeholders recruited?

Survivors, family members, health care providers, lay responders, and other stakeholders including researchers were invited to participate through emails, newsletters, and advertisements sent to relevant Canadian health professional associations, survivor and family member support groups and networks, through the professional networks of steering committee members, and posted on social media. This was a non-probabilistic self-selection sampling strategy, however at the three-week mark of the survey being open, respondent demographics were reviewed and

targeted communications were used to encourage response from underrepresented groups.

## Were stakeholders actively involved or did they just participate?

Stakeholders not only participated but were also actively involved in the research prioritization process: They were part of a steering group with diverse OHCA experiences and perspectives consisting of 2 survivors, 1 family member, 4 clinicians (2 emergency department physicians, an intensive care unit nurse and a paramedic), 2 resuscitation