Survivor Research Involvement Ladder

Role	Research Activity	Planning and Decision-making	Researchers	Data	Analysis	Dissemination	Accessibility
Survivors lead research.	***** Survivors decide what to research. They design and undertake all aspects of the research project. The conduct of the research meets all the principles of the Survivors' Charter.	***** Survivors make all key decisions. They decide the purpose of the research and lead the planning and preparation, including securing funding.	***** All the researchers are survivors. They receive appropriate training, support and recompense.	***** All the data is from survivors and reflects their voice.	***** The analysis is from the survivor perspective and they write the report.	***** Survivors lead the dissemination of the results. They are clear what impact they hope the research will have and lead the evaluation of this.	****** The report is freely available through open access and is accessible to survivors
Survivors co-produce the research.	**** Survivors are involved as equal partners in all stages and aspects of the research. The conduct of the research meets most of the principles of the Survivors' Charter.	**** Survivors share decision-making. including the purpose of the research and the planning stage. They may assist to secure funding.	**** Most of the researchers are survivors and all are trauma-informed. They receive some training and support, and may be recompensed.	**** All the significant data is from survivors. It may be supported by data from others.	**** The survivor perspective is central to the analysis. Survivors share in writing the report.	**** Survivors are central to the dissemination of the results. They share discussions about what impact the research may have. They take part in any impact evaluation.	**** The report is freely available to survivors.

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Survivors act as advisers to the research project.	*** Survivors act as advisers on research design and delivery and may share some aspects of the research activity. The conduct of the research meets some of the principles of the Survivors' Charter.	*** Survivors do not have the final say on decisions but their views are acted on. The purpose is already decided and funding secured.	*** Some of the researchers are survivors and most are trauma-informed. There is limited training and support for survivor-researchers, and token recompense, if any.	*** Key data is from survivors, and data from others e.g. professionals, supporters, family, may be included.	*** Survivors may have contributed to the analysis but their views are not central.	*** Survivors may inform the dissemination process. Survivors may be asked about desired impact, which may not be evaluated.	*** The report is available to contributors, but there may be a cost to the public.
Survivors are consulted about some aspects of the research.	** Survivors are consulted about research questions and themes and their views have some impact. There is limited correlation with the Survivors' Charter.	** Survivors may be consulted about some aspects of the research content. They do not have a say in decisions. The research purpose and design is already decided.	** A minority if any of the researchers are survivors. Some may be trauma-informed. There is little if any training or support for survivor-researchers, and no recompense.	** Data is from survivors, families and professionals in similar proportions.	** Survivors did not contribute to the analysis and reporting although their views may be quoted.	** Survivors have no involvement in the dissemination process. There is no evaluation of impact.	** The report is available to academics, for a fee.

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Role	Research Activity	Planning and Decision-making	Researchers	Data	Analysis	Dissemination	Accessibility
Survivors are only subjects or participants of the research.	* Survivors are subjects of the research and may be participants. The research project does not meet the principles of the Survivors' Charter.	* Researchers make all the decisions. Survivors are not consulted about any aspect of the research.	* There are no known survivor researchers. Few if any are trauma-informed.	* Key data is from professionals and/or families as much as or more than survivors. Survivors may be only talked about, or may be participants.	* The report does not reflect survivor perspectives and their voices are not significant.	* The report has minimal dissemination outside of the research context. There is no consideration of impact.	* The report has minimal availability outside of the research context.

Notes on using the ladder

1. The first column, focussed on overall role, represents the main rungs of the ladder. The other columns try to indicate what this might look like in practice, covering key areas of research activity. The focus is on how central the survivors are to all aspects of the research project. The best research involvement is survivor-led from the initial idea to impact evaluation.

2. The rows contain indicators and as such a project may not score evenly on one row. If desired, a scoring matrix as indicated by the stars * can be used to give an overall ranking. So a project may score 5* in Analysis column, but only 3* in dissemination.

3. Our Survivors' Charter, *From Pain to Power,* is used to provide an indicator of the ethical approach to survivor involvement, the values of the research project and how well issues such as safety are managed. Further details of all these are in the Charter.

4. There are some assumptions behind the ladder, which we hope are clear. We believe that the perspective of survivors can positively change decisions about what is researched, how it is conducted, what meaning is drawn from the data and where it is disseminated. In our view this is best achieved when the research is led, conducted and analysed by survivor-researchers, whether research professionals or volunteer peer-researchers.

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Survivor Research Involvement Ladder

5. We support open access to research and recognise the exclusivity of reports published in academic journals that are only available to subscribers. For this reason we have included accessibility as the final column.

6. Commonly the motivation for survivors to be involved in research is on order to see a change/improvement in policy, services and practice. For this reason we have included an impact focus and measurement in the penultimate column.

7. We recognise that there may not be sufficient information to make a clear judgement in each area; for example, there may be survivor-researchers who choose not to label themselves as such. Their perspective may still influence the research, but if it is not explicit we consider the impact will generally not be as great. The indicators here may help to identify a potential limitation to the research, or areas for improvement.

8. Clearly there can still be valuable research in relation to trauma and abuse that does not involve survivors, or there may be some where it is not always appropriate or possible, for example abuse of people who lack capacity. In the majority of cases, however, we believe involvement is both possible, ethical - “nothing about us without us” - and essential to getting the best results, that fully and accurately represent the experiences, views, wishes and feelings of survivors – the survivors’ voices.

9. **Pilot Evaluation**

We are making this version of the Involvement Ladder freely available, as an extended pilot of our first pilot version, which was tested by Simone Kennedy in her MSC research Project. We encourage everyone using the Ladder to register with Survivors Voices, so we can seek your feedback. We are keen to identify collaborators who are interested in developing this work further, including joint funding bids to support such development. If you are interested in collaborating, please contact connect@survivorsvoices.org. If you have not already done so, please register your interest on our website www.survivorsvoices.org/involvement-ladder

Inspired by the work of Sherry Arnstein and Roger Hart and their ladders of participation.

Pilot version 2. Jane Chevous, Concetta Perôt, Simone Kennedy 2019.

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