A SHARED LEARNING AGENDA FOR INCLUSIVE HEALTH RESEARCH IN HUMANITARIAN SETTINGS

EQUAL
EVIDENCE & IMPACT FOR MOTHERS & NEWBORNS LIVING IN CONFLICT

INTERNATIONAL RESCUE COMMITTEE

RECAP
HELPING TO IMPROVE HUMANITARIAN RESPONSE
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EXECUTIVE SUMMARY

While there are notable guidance documents on inclusion in humanitarian programming, gaps remain in advocating for strategies and standards that reflect the fundamentals of inclusion in research processes. The premise is that throughout the research process, there are multiple opportunities to engage in inclusion. To inform future research guidance and generation, the International Rescue Committee (IRC) commissioned a review of technical guidance documents focused on how to ethically and equitably include marginalised population groups in humanitarian health research. The review identifies key gaps in the existing guidance and outlines recommendations for a shared learning agenda for inclusive research. Recognising that innovative and inclusive programming is based on good inclusive research practices, the documents included in the review may serve as practical resources that can be consulted, adapted, and applied to humanitarian-based health research.
## ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
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<tr>
<td>AGD</td>
<td>Age, Gender, Diversity</td>
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<tr>
<td>DRR</td>
<td>Disaster Risk Reduction</td>
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<tr>
<td>HIS</td>
<td>Humanitarian Inclusion Standards</td>
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<tr>
<td>IDP</td>
<td>Internally Displaced Persons</td>
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<tr>
<td>IRC</td>
<td>International Rescue Committee</td>
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<tr>
<td>LGBTQIA+</td>
<td>Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, Asexual</td>
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<tr>
<td>LMIC</td>
<td>Low-to-middle income countries</td>
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<tr>
<td>NGO</td>
<td>Non-governmental Organisation</td>
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<td>OPD</td>
<td>Organisation for People with Disabilities</td>
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<td>PAR</td>
<td>Participatory Action Research</td>
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<tr>
<td>POC</td>
<td>Persons of Concern</td>
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<tr>
<td>PWD</td>
<td>Persons With Disabilities</td>
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<tr>
<td>RO</td>
<td>Representative Organisation</td>
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Research in humanitarian settings is increasingly valued for generating contextualised knowledge that helps actors better respond to the needs of people affected by humanitarian crises. There are expectations that people affected by crisis and those who represent their interests and advocate for their rights, be active players in shaping research agendas and participating in research processes. Without inclusive research and quality data, humanitarian actors are unable to effectively understand whether people – in all their diversities – are included in monitoring humanitarian health responses and interventions, undermining the implementation of human rights declarations and conventions.

The premise is that inclusive and meaningful participation in research leads to the design and implementation of more impartial and appropriate interventions and solutions to health challenges across diverse humanitarian settings.\(^1\) To this accord, the relationship between research and programming are often seen as overlapping because research informs innovation and overall humanitarian response; but also because much of what is done in innovation must be supported by research.\(^2\)

**WHAT IS INCLUSIVE RESEARCH?**

It has been nearly two decades since disability academics Johnson and Walmsley first introduced the inclusive research paradigm in their text titled *Inclusive research with people with learning disabilities: past present and future*.\(^3\) They depict [disability] inclusive research as that which ‘involves people who may otherwise be seen as subjects for the research as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users’.\(^4\) Inclusive research is ‘emancipatory’ – it is about doing ‘with’ rather than doing ‘for’ or ‘to’, which is a key concept of the disability rights movement (i.e Leave No-one Behind).

Approaches to inclusive health research need not be uniform, but must encompass core elements of inclusion. A rights-based approach is central to inclusion, as well as the participation of beneficiaries and their representatives in the research process – where people ‘benefit from each other’s expertise to generate new knowledge’.\(^5\) Inclusion provides a reality check and seeks to address important research questions that could not otherwise be answered.\(^6\) A fundamental goal of inclusive research is reaching participants, communities, and knowledge that would otherwise not be accessed. Involving co-researchers in the decision-making and the execution of research is a defining trait of participatory and inclusive research.\(^7\) It involves accessibility and targeted identification and recruitment of under-served communities. Leadership by local organisations, using local skills, experience and expertise, and active participation in decision-making and planning processes can further facilitate inclusive research coordination.\(^8\) Furthermore, partnership equity and accountability can translate into knowledge generation that features the voices of marginal groups, strenghtening advocacy efforts – another essential element that fosters inclusion.\(^9\)
Inclusive research processes should also provide an opportunity to change the unequal power relations between researchers and those being researched. Advocates for inclusive research emphasise that research processes and results should not have a detrimental impact on participants (i.e. doing safe research). Inclusion should result in capacity sharing and social transformation for all involved – meaning co-researchers actively engage in health agendas and interventions that meet their own needs. Sharing capacity moves away from a top-down and passive approach to inclusive research, and acknowledges the co-researchers have existing expertise to contribute.

The majority of research methods specifically labelled as inclusive exist in the field of disabilities, however, there are diverse approaches to inclusive research that make inclusion an evolving set of practices, rather than a rigid methodological framework. There are four key sets of inclusive research practices — participatory, emancipatory, participatory action, and partnership/user-led research. For this review, the core elements of an inclusive research life cycle broadly include participation, partnerships, ethics and impact/social transformation. For effective and impactful research, these core elements must guide the entire research life cycle; from conceptualisation, planning the design ethics protocols, data collection, analysis, validation, and dissemination (see Figure 1).

**Figure 1 Core elements of inclusive research**
The question that remains is: How can academics, researchers, non-governmental organisations (NGOs) and development agencies stimulate and generate research that can support real change towards inclusion? To begin to address this question, the IRC commissioned a desk review and gathered technical guidance on how to ethically and equitably conduct research on health issues facing marginalised population groups in conflict and humanitarian settings. The review highlights particular resources that can be consulted, adapted, and applied to humanitarian-based health research as necessary.

**OBJECTIVES**

1. Identify guiding documents/resources currently being used to enhance inclusivity in humanitarian health research.

2. Document best practice examples for the inclusion of marginalised groups in health research in humanitarian contexts and identify gaps in existing guidance documents.
SEARCH STRATEGY

The focus of this review is on under-represented populations or communities in humanitarian settings, including a spectrum of marginal identities whom are often neglected in health research – i.e. internally displaced persons (IDPs) and refugees (1) with disabilities, (2) who are transgender or gender nonconforming, (3) are 65 years or older, (4) are undocumented or have non-camp status, (5) have other intersectional identities.

An online search was conducted using Google to identify documentation on inclusive research guidance and practice in humanitarian settings. This review focuses on guidance notes, needs assessments and monitoring tools, scope of practices, technical guidelines, tip sheets, and quality assurance frameworks for inclusive research as opposed to specific research designs, methodologies, theories of change, and case studies from the field. The reviewer also searched more than 30 websites of organisations and developmental agencies active in humanitarian emergencies (Annex 1).

Search terms were broad and indicative of “inclusion in humanitarian health research”. Search terms used multiple combinations, including: human rights, rights-based research, adolescents, young people, older persons, transgender, sexual orientation, disability, disabilities, diversity, refugee, marginal, humanitarian crises, health research, research practice, guideline, toolkit, toolkit humanitarian research, guidance humanitarian research, disaster, conflict, emergency.

The inclusion criteria for documents were: (1) marginal populations affected by conflict, 2) available in English; (3) available online or in-house/internal to IRC. For the screening process, an in-document word search (using “find” CTR+f) helped to identify relevant documents for inclusion in the full-text appraisal. Words used were inclusi;, exclusi; participat; marginal; disabil; gender; LGBTQ; transgender; diversity; marginal; documented; non-camp.

If no words were identified in the full-texts, the document was excluded from review.

While the most common target groups for ‘inclusion’ in research and programming have been gender, guidance focused specifically on being gender-responsive (with no mention of non-conforming gender identities) were excluded as the review sought to concentrate on the most marginalised intersecting identities that have received less consideration in health research.15

The included documents were summarised by type, objectives, specific target group, and target audience in an evidence table and discussed narratively.
APPRAISAL FRAMEWORK: THE PRINCIPLES UNDERLYING INCLUSIVITY IN HUMANITARIAN SETTINGs

No pre-specific appraisal checklist was identified. Rather, the review applied existing inclusion standards to help operationalise inclusive health research in humanitarian settings. It was expected that inclusion in health research guidance should reference any of these principles.

- Inclusion Charter: five steps to impartial humanitarian response for the most vulnerable (2016)
- Core Humanitarian Standard on Quality and Accountability (2014) (see Figure 2).
- HI project quality assurance framework (no date)

Considering the broad terms and approaches for inclusive health research, and the lack of standards for inclusive research in humanitarian settings, the standards and frameworks above outline an ambition to make humanitarian research and action more inclusive and relevant, by advocating rights-based models, involving communities affected by crises and practitioners in the design and implementation of research, collaborating with research institutions in crisis-affected areas, and making research knowledge accessible beyond traditional conferences and publications (These ideas are picked up in the Australian Red Cross’s 2017 publication Localising the Research Process).
The Inclusion Charter proposes five steps to impartial humanitarian response related to participation, data, funding, capacity and coordination. More recently, the new Inter-Agency Standing Committee (IASC) guidelines around disability inclusion seeks to understand ‘how the various segments of the affected population are consulted especially in the prioritization of needs, decision-making processes and the ways in which limitations to participation and inclusion are addressed’.23

The identified documents were further appraised for relevance, quality and impact using a framework outlining inclusive research metrics/elements garnered from a background literature review (see Figure 3).

### Inclusive Research Criteria (Embedded in Core Elements)

<table>
<thead>
<tr>
<th><strong>Relevance</strong></th>
<th><strong>Quality</strong></th>
<th><strong>Impact</strong></th>
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<td>• Global South Universities</td>
<td>• Inclusive funding</td>
<td>• Fill the knowledge gap</td>
</tr>
<tr>
<td>• Rights based approach</td>
<td>• Awareness (address discrimination) training / capacity</td>
<td>• Research for social change and empowerment</td>
</tr>
<tr>
<td>• Identification and outreach</td>
<td>• Partner with encourage OPDs and clients to participate in/lead design, planning, safety protocols, recruitment, ethics training, data collection and analysis, and dissemination of findings</td>
<td>• Partner equitability and sustainability</td>
</tr>
<tr>
<td>• Responsive to health priorities</td>
<td>• Inclusive coordination and resources mobilization</td>
<td>• Accessible and equitable research translation and dissemination</td>
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<tr>
<td>• Timely/responsive</td>
<td>• Ethical / Do no harm</td>
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OUTCOMES OF SEARCH

The search was conducted in October-November 2021. Thirty-one guidance documents were identified, and 21 were included from 16 different organisational websites. Eleven documents focused exclusively on research specific processes, methodologies, or strategies – the others focused more broadly on inclusion in implementation and programming – the premise being that guidance on inclusive programme implementation can inform good practices for advocating for inclusive research.

The type of documents ranged from monitoring and needs assessment tools, guidance notes, methodological and fieldwork toolkits, training manuals, and checklists. All of the documents were specific to humanitarian contexts. One tool highlighted the importance of [disability] inclusion in natural disaster management and response (#5).

Group representation for inclusion among the documents was highest for persons with disabilities (#2, 6, 7, 12) including co-researchers with intellectual disabilities (#13), older persons and persons with disabilities (#11, 15, 16, 17, 18, 19). Three included LGBTQIA+ persons (#8, 10, 20). One guidance note focused on working with refugees engaged in sex work (#21) and another one with a population of interest being non-camp or urban refugees (#3). Three documents were non-group specific. Target audiences included humanitarian stakeholders overall – humanitarian agencies, partner organisations, funders, programmers, and health practitioners – with some documents targeted specifically to research and programme developers and research team members – including fieldworkers, enumerators, and evaluators (see Search Flow Diagram Figure 4).
Figure 4 Search Flow Diagram

**Documents identified through organisation websites (n=27)**

**Additional documents identified through other sources (n=4)**

**Documents screened using word search (n=31)**

**Documents excluded (n=10)**

**Full text reviewed (n=21)**

**Type of documents**
- Toolkit monitoring tools/needs assessment tools, guidance note, manual

**Objective**
- Integrate group specific needs into programming & research
- Guidance for data collection & disaggregation

**Group Specifics**
- Disability n=5 (IDD=1; older=6) N=11
- Non-camp/urban n=1
- LGBTI n=3
- Adolescents n=1
- Sex workers n=1
- Non-specific n=3

**Type of audience**
- Health Practitioners
- Fieldworkers/researchers, enumerators
- Humanitarian agencies
- Partner organisations

**Included**
- Eligibility
- Screening
- Identification

**Documents identified through organisation websites (n=27)**

**Documents screened using word search (n=31)**

**Documents excluded (n=10)**

**Full text reviewed (n=21)**

**Type of documents**
- Toolkit monitoring tools/needs assessment tools, guidance note, manual

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- Sex workers n=1
- Non-specific n=3

**Type of audience**
- Health Practitioners
- Fieldworkers/researchers, enumerators
- Humanitarian agencies
- Partner organisations
While most guidance focuses on strengthening inclusion in humanitarian action response more generally, the collated resources are helpful in thinking about inclusion in research. From the documents identified, only half – 11 - are applicable to conducting inclusive research (#1; 2; 3; 4; 5; 6; 8; 9; 13; 14;15). The evidence table in Annex 3 presents the summarised guidance generated from the desk review.

As an introduction resource, the Chicago Council on Global Affairs’ (CCGA) Bridging the Research Gap: A Toolkit on Inclusive Research and Development Practices (#1) presents a list of steps to ensure the entire research and development process—from idea inception to the dissemination of products/information—takes into account equity, diversity, and inclusion. It includes five steps for inclusive research practices, and additional tools to help implement inclusive research and development practices. Importantly, the toolkit offers a lot of attention to diversity within the research team, considering intersecting identities, using pronouns, covers accessibility, and user friendly platforms for dissemination. The toolkit acknowledges that research must empower communities of focus.

Arbeiter-Samariter-Bund (ASB) Indonesia and the Philippines and ELHRA published a comprehensive guidance document called “Everyone can be involved in research" Practical Guidelines for Co-researching with Persons with Disabilities (#2). This is a comprehensive document covering all aspects of the research process, and is a valuable tool worth consulting and applying to all marginalised groups in humanitarian settings. The documents covers establishing partnerships with OPDs as research partners, developing a budget for participatory research, and strengthening the capacity of co-researchers for ethics compliance, data collection in targeted areas, and inclusive dissemination of the research results. The lessons learned while undertaking disability inclusive research provide valuable anecdotes to the challenges and benefits of inclusive research.

The Research for Health in Humanitarian Crises (R2HC) / ELHRA / HIF programme presented a comprehensive report of a methodological assessment of 60 case studies in conflict-affected areas (#3). Case studies included those that facilitated research collaboration with PoC and their representative NGOs and government structures. It is a good example document for consultation when researchers are working with humanitarian practitioners to design and conduct research. The report upholds the value of participatory approaches at all stages of research, and as such, the R2CH programme requires all their funded research is jointly implemented by academic groups in collaboration with at least one humanitarian partner. The report acknowledges the barriers of conducting rigorous research in humanitarian settings and explores adaptations and innovations of research methods in light of restraints typified by insecurity, limited existing research infrastructure, and limited availability of adequately trained research staff.
The document highlights key methodological issues related to sampling, bias and generalisability, fieldwork logistics, and the challenges of getting informed consent – including a lack of ethical considerations and description in the studies reviewed. The report calls on funders to establish more rigorous requirements for researchers to document methodological changes.

**Save The Children’s Participatory Action Research (PAR): a ‘how to’ guide for use with adolescents in humanitarian contexts (#4)** uses lessons from the field to embed guidance on inclusive health research, and importantly – PAR. The toolkit covers the whole research process from planning – including identifying funding sources, outreach and recruitment of participants, and staff and community engagement in data collection, analysis, and dissemination. This document sets out clear guidance for selecting relevant research topics and appropriate research tools, capacity strengthening and training of staff, consultants and youth facilitators, protecting and safeguarding research staff and participants, and analysing and documenting findings in manners that are representative of the group concerned.

**The ACF International “Participatory risk, capacity, and vulnerability analysis: a practitioner manual for fieldworkers” (#5)** is intended to provide methodological and practical guidance to ACF field workers on implementing Participatory Capacity and Vulnerability Assessment (PCVA). The diverse tools and guiding questions for disaster risk analysis facilitate a participatory process through collaborative learning. It is designed to stimulate dialogue and information sharing between ACF’s field workers, community members, and local partners, and focuses on those who have less ability to recover from disasters. The PCVA is a flexible tool that must be tailored to suit the needs of a particular context.

 Guidance documents from **Humanity & Inclusion (#6, 7)** advocate for the collection of disability disaggregated data. They further advocate non-discrimination, targeted identification of participants, and consultation and planning with persons with disabilities and their representative organisations. The documents advocate for PAR and training to ensure the collection of quality and reliable data on inclusivity. They advocate that all information provided be accessible and relevant to persons with disabilities.

**IRC guidance documents** advocate for equitable partnerships with local, national, and regional organisations, groups, and networks. Specifically, the “We Know Nothing” document (#8) recognises and value the expertise that LGBTQIA+ people have on their own realities, and the role LGBTQI persons play in assessing their own risk and safety. The IRC’s Airbel Lab guidance document on Equity Research Standards (#9) is relevant, of high quality and considers how inclusive and equitable research teams and strategies can have positive impacts for all stakeholders. The document acknowledges how power differentials can be affected by and exacerbated by the research process, as well as the value of community input sessions and global and national advisory groups of activists, researchers, and practitioners. In addition to developing locally-driven research agendas, advocacy is needed to cultivate long-term research partnerships with in-country researcher and research institutes with regular adaptation, feedback and validation workshops and bidirectional knowledge production.
These partnerships should be non-extractive and avoid perpetuating harm with local communities. The IRC has also committed to channelling at least 25% of its funding to local partners (e.g., civil society, local government, private sector actors). The standards include safety when collecting disaggregated data for intersectional analysis, and how pre-analysis plans should include information on how data will be assessed for effect modification within evaluations by intersecting identities. IRC Airbel Lab is one of only two documents that addresses representative, equitable, and accessible dissemination. The standards indicate that findings and recommendations are co-created, and dissemination should occur through co-authorship and co-presenters from local research team members. Sharing research findings in an accessible format, including back to participants is considered pertinent to coming full circle in inclusive research.

The IPPF Strategic framework “Inclusion in Humanitarian Action: LGBTQIA+ vulnerabilities and capabilities in crises” (#10) offers guidance on inclusion of LGBTQIA+ persons in humanitarian action. While not research-orientated, the framework’s objective is to include the experiences of diverse LGBTQIA+ facing humanitarian crises, and ensure safe and sensitive collection of data, for evidence-informed policy, practice, and advocacy. The framework recognises the capabilities of marginalised persons, and requests guidance to ensure diverse LGBTQIA+ inclusion in developing indicators for monitoring progress.

The Humanitarian Practice Network’s (HPN) provides a range of tools and guidance for disability and older age inclusion. The SADI “safe, accessible, dignified and inclusive approach” (#11) document is grounded in a holistic and intersectional approach and promotes the use and analysis of sex, age, disability, and diversity data. The resource promotes community engagement and strengthening capacity of staff and partners. It advocates for the use of feedback mechanisms to improve accessibility and to enable a culture of accountability to communities.

The ICRC self-assessment/monitoring inclusion tool (#12) is intended for programmers to promote disability inclusion. It holds researchers accountable to their participants’ rights and needs. It is a one-page disability-specific guide that is user friendly and can potentially be adapted for monitoring inclusive research with diverse marginalised groups.

YELL Lab’s “Toolkit for Remote Inclusive Research” in emergency settings (#13) is specifically designed for research team leaders including research team members with intellectual disabilities. It describes strategies that can be used across different stages of a research process. For each strategy, the toolkit includes suggestions of free and low-cost technologies and resources that teams can use to collaborate remotely with PoC and their representatives and provides examples of other research projects that have used each strategy and accommodations they advocate.
The ODI and Humanitarian Policy Group (HPG) State of Play document (#14)\(^37\) incorporates inclusive research elements. Chapter 5 of the report specifically presents how research can support progress towards inclusive humanitarian action. It advocates that disaggregated data collection and intersectional analysis be mainstreamed into existing research tools. There is a recognition of how organisations representing marginal groups have narrow mandates and incentives for research collaboration and may lack capacity and resources to consider partnerships. The document also tackles the dilemma of statistical power and how reaching the highest number of participants may impact on inclusion of more marginalised groups.

The CBM rapid needs assessment guidance (#15)\(^38\) and the ADCAP good practice guide (#16)\(^39\) provide humanitarian tools on how to engage with persons with disabilities and older age. Together, themes for inclusion include mainstreaming inclusion within organisations structure and developing an institutional poll of ‘inclusion champions’ to challenge cultural and social attitudes towards older people and people with disabilities. Furthermore, it is good practice to sensitis field staff on data collection and disaggregation across the age, gender and disability (AGD) spectrum. Disabled and older people and their representative organisations should have leading roles on data exchange and prioritising needs, and assessment teams should include someone with disability/aging experience. Furthermore, the CBM calls for accountability to conventions and standards for inclusion and consider the ethics and safety of all involved. The ADCAP Good Practice Guide (#16) provides further step-by-step guidance for interacting with persons with disabilities.

HelpAge International’s guidance documents provide practical recommendations for inclusion using a rights-based approach. They support strengthening evidence by routinely collecting and using disaggregated data and analyses of humanitarian needs; challenging discrimination of older persons and persons with disabilities (#17).\(^40\) Their report provides recommendations for inclusion in all stages of response, by identifying the specific needs and capacities of older persons and supporting local organisations to include them in the response (#18)\(^41\). Additional guidance on training for inclusion in humanitarian programming and response calls for donors to provide more resources on top of programmatic funding for inclusion initiatives, and to develop a community of practice and training resources across all organisations to share learning and resources (#19). The recommendations are to develop a one-stop-shop training portal for inclusive resources that provides links and pointers for time-poor staff to browse through. The document calls for assessing the reality of how, and during what phases, the Humanitarian Inclusion Standards can be operationalised (#19)\(^42\). It is important that formalised standards for inclusion guide inclusive health research too, and this training document helps to operationalise what inclusion can look like.
InterAction/USAID’s Roadmap for Research (#20) provides guidance for research inclusive shelter and settlements responses. Throughout this guidance there are applicable elements to consider when including LGBTQIA+ (and other PoC) in humanitarian health research. The document advocates for researchers to use mixed methods and PAR approaches, and that research be guided by representation, comprehensiveness, contextualisation, inclusivity, and strengths-based approaches. The Roadmap recognises the diversity of contexts and intersectionality of LGBTQIA+ and generating knowledge from multiple studies in different humanitarian contexts to inform future responses. The contextualised approaches to knowledge production include ensuring country researchers have the knowledge, skills, and networks to reach and understand the lives and needs of marginalised groups; using inductive approaches to data gathering and analysis; centering ideas which challenge accepted practice, research, and thinking; and taking an inclusive and strengths-based approach by working with diverse LGBTQIA+ communities and civil society as researchers of their own lives and designers and implementers of responses.

The WRC’s “Working with Refugees Engaged in Sex Work: Practical steps for field staff” (#21) advocates a right-based approach and soliciting the input of affected individuals at every stage of design and implementation. While not research-specific, the note can be useful in thinking about what works to engage sex workers in humanitarian health research. It advocates for the use of evidence to guide person-centred programming and support, and engaging with local, national and regional organisations or service providers who have experience working with local sex worker communities, including sex worker-led organizations. The steps may be adaptable to health research design that is person-centred and involves representative organisations in the research process.
KEY GAPS IN GUIDANCE FOR INCLUSIVE RESEARCH IN HUMANITARIAN SETTINGS:

Reflecting on the limitations of the reviewed documents, the following gaps are acknowledged:

- Missing identities
- Intersectionality and diversity disregarded
- Funding challenges overlooked
- Drivers of exclusion ignored
- Missing details on inclusive methodologies
- Ethics and safety not considered
- Limits to participation and local ownership of research
- Lack of guidance on shared dissemination and research translation
- Lack of guidance on identification and outreach
- Costs not considered
- Lack of information on outcomes and impact (cases of inclusion)

**Missing identities**

While a good deal of focus has been on the inclusion of persons with disabilities and older persons, limited guidance focused on youth – especially girls, non-conforming gender groups, non-camp refugees, refugees engaged in sex work, and refugees with differing legal statuses. The question is why are these groups missing? Is it due to a lack of guidance on identification and outreach? Or a preference of random over purposive sampling and recruitment.

There is limited guidance for identifying and targeting marginalised persons that may remain ignored.

**Intersectionality and diversity disregarded**

Guidance is less focused on inclusion strategies for persons with intersecting marginal identities: such as younger persons with disabilities or non-conforming sexual identities, refugees and IDPs with varying legal statuses, a non-camp based migrants with heightened health risk due to disabilities or a person with mixed marginal identities. Limited reflection on diversity within marginalised groups affects reliable and meaningful disaggregation and analysis of data.
Funding challenges overlooked
The criteria of funding can often limit the resources needed to make research more inclusive, and there is an absence of dedicated funding streams and few incentives or mandates for inclusion. While some documents acknowledge the paucity of appropriate funding for inclusive research endeavours, and lack of funding for local organisations to participate in research, there is insufficient guidance directed to donors and funders specifically.

Drivers of exclusion ignored
While technical approaches to inclusion are necessary, they are not sufficient. To address health challenges, a better understanding of the multi-dimensional drivers of inclusion and exclusion – how they relate to each other and intersect – is needed. This requires in-depth local knowledge and understanding of the humanitarian context, and partnering with local ROs and recruiting co-researchers from affected groups.

Missing details of inclusive methodologies
It is promising that some of the documents advocate for PAR designs and mixed methodologies, however there are existing methodological gaps in the guidance. There are few details on which specific methods work best for inclusion, and nothing on how to overcome challenges in applying these inclusive research methods in humanitarian settings (i.e. what are the limitations of PAR).

Ethics and safety not considered
Research in humanitarian settings is often challenging, and requires an ethical approach that ensures safety throughout the research process. While the reviewed documents can inform better inclusive research strategies, they lack consideration of the risks and benefits of conducting research within the communities and in partnership with communities and local organisations.

Limits to participation and local ownership of research
There is little guidance to ensure research is guided by local expertise. Disability scholars note that “the practical realities involve ensuring that people who are moving to positions of partnership in research are neither over-burdened nor over-protected”. However, the reviewed documents do not seem to tackle the limits to participation or challenges to local ownership of research. Furthermore, guidance is heavily focused on risk and vulnerability with little recognition of the skills and capacities of marginal groups as co-producers of research.

Cost not considered
There is little acknowledgement of how inclusive research may carry additional costs. While there is some reference to needing donors' buy-in for inclusion; and for adjusting budgets to allow for reasonable accommodations, strengthening skills of co-researchers, and accounting for costs for targeted identification of marginal groups, the documents fall short on guidance to overcome the many financial barriers to inclusive research.
**Lack of guidance on inclusive dissemination and research translation**

How and where knowledge is published can determine uptake and impact of inclusive research, however few resources focus on strategies for shared dissemination and research translation that go beyond funder reports and academic publications and conferences.

**Lack of information on outcomes and impact**

While the resources included have relevance and quality in lieu of the elements and strategies they reference, the ‘impact’ of inclusive research remains vague. There is little evidence that any recommendations or guidance for inclusive health research have been implemented in humanitarian settings, and what the beneficial outcomes are – e.g. How is inclusive research with marginal identities conceptualised as empowering or good practice. This knowledge gap is significant.

Annex 4 sets out the barriers or problems with inclusive research practices and includes recommendations for specific or all stakeholders while referencing the resource document for further consultation. Future work on what is needed for inclusive research in humanitarian settings could help to refine these recommendations for more standardised guidance.
ENTRY POINTS FOR INCLUSIVE HEALTH RESEARCH IN HUMANITARIAN SETTINGS

While conducting research in humanitarian settings may be challenging, there are inclusive strategies stakeholders can employ to ensure research is relevant and representative of marginal groups.

The following entry points are advised for donors and funders, research institutions, research teams, and local humanitarian organisations. These questions (called the Inclusion Test) can be used to interrogate strategies at different stages of the research processes and for different stakeholders to consider.

<table>
<thead>
<tr>
<th>THE INCLUSION TEST: WHAT DO WE NEED TO ASK OURSELVES?</th>
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</thead>
<tbody>
<tr>
<td><strong>Funders/Donors</strong></td>
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<tr>
<td>• How do we hold funders and donors accountable to inclusive research proposals?</td>
</tr>
<tr>
<td>• How do we fund research that is not rigid and allows for an intersectional participatory research strategy?</td>
</tr>
<tr>
<td>• Can funders and grant making bodies be progressive or flexible enough to allow for innovative grant proposals and methodologies that may not be considered ‘robust’ enough?</td>
</tr>
<tr>
<td>• How can donors ensure budgets allow for cost-effective inclusive research? What adjustments are needed in budgets to allow for the provision of reasonable accommodations or targeted outreach for recruitment?</td>
</tr>
<tr>
<td><strong>Research institutions and researchers</strong></td>
</tr>
<tr>
<td>• What policies are in place to explicitly mainstream inclusion in steering committees, ethics boards, supervision, and health research projects? In what ways and at what stage can the research include representatives of the marginalised groups on research steering committees or other similar committees?</td>
</tr>
<tr>
<td>• Are staff aware of humanitarian standards for inclusion and rights of marginal groups? Is there training and awareness of rights for all staff?</td>
</tr>
<tr>
<td>• What possibilities exist for researchers with marginal identities to be represented in the research team? How are they included in identifying research contexts, planning research, methodologies, implementation, and dissemination?</td>
</tr>
<tr>
<td>• How do we ensure there is participation from research institutions in the Global South / countries with on-going conflict?</td>
</tr>
<tr>
<td>• What strategic partnerships can be forged between research/academic institutions and specialised humanitarian stakeholders (representing marginal groups) to ensure an inclusive approach to research?</td>
</tr>
</tbody>
</table>
Research institutions and researchers (continued)

- How does the research assist or empower the community/PoC and their representatives?
- How do we ensure that co-researchers are not overburdened?
- How do we address the barriers to inclusive research such as lack of time and funding constraints? What are the most cost effective strategies for inclusive research?
- What does capacity strengthening for an inclusive research team look like?
- What methodologies are suitable to ensure participation? How inclusive of people’s different [marginal] identities are the data collection tools (e.g. pronouns, language and accessibility)?
- Do we have data disaggregation plans? How do we account for intersecting identities?
- How do we monitor whether research is inclusive?
- How can we make research knowledge accessible beyond traditional conferences and publications.

Local representative organisations

- How can we promote partnership equity?
- What role does allyship play in partnerships for inclusive research?
- How do we ensure research organisations foster long-term and non-extractive partnerships to avoid perpetuating unintended harm with marginal groups?
- How can research organisations play a role in using findings and disseminating for advocacy?
KEY MESSAGES FOR A SHARED LEARNING AGENDA

- **Cultural shift:** We must acknowledge that there are inclusive research strategies – we just need implementation.

- **Collaborate:** Collaboration leads to research that serves everyone. There is a need to institutionalise inclusive research practices in partnership with donors or funders, research institutes from the Global South, and representative organisations.

- **Eliminate silos:** We need to learn from each other, share experiences, and eliminate silos. Humanitarian research organisations should work to enhance inclusion within their organisation and in their research development and practices. Establishing a community of inclusive practice would be a worthwhile endeavour.

- **Adopt a rights-based approach:** Research must be responsive to the human rights of marginal groups and use rights-based language in calls for proposals, protocols, scope of inquiries, and reports.

- **Twin-track it:** Both mainstreaming health research and including targeted strategies for inclusion are recommended. This is known as the twin track approach, which can ensure technical guidance for the inclusion of specific groups, while also tackling larger questions around the prioritisation of outreach and identification and consistent collection of data among marginalised groups for comparable and reliable intersectional analysis.

- **Fill the knowledge gap:** Integrating lessons from the field on what works for inclusion is likely to lead to knowledge generation and can help research to become more effective in reaching those previously unreached.

- **Monitor inclusion:** We need learning and evidence on what elements for inclusive research work and what does not (when combined, adapted, or innovated in the field). We need to engage more actively to define monitoring indicators for inclusion (e.g. see Light for the World's Road's to Inclusion Tool).
CONCLUSION

While there are notable guidance documents on inclusion in humanitarian programming and research, the localisation of humanitarian research has been slow, and gaps remain in advocating strategies and standards that reflect the fundamentals of inclusion. If we hope to achieve various ambitious global health targets (such as the Sustainable Development Goals), we need to think about inclusion early and often. Inclusion is an iterative process rather than a set destination. There is no silver bullet to conducting inclusive research. A collaborative action plan is needed to prioritise best inclusive research criteria to help us be accountable to the principles of impartiality and leaving no one behind.

LIMITATIONS IN THE SCOPE OF THE REVIEW

The scope of the review was limited to existing documentation of inclusive research tools and guidelines. A more systematic identification of what works when resources are consulted, adapted, and applied is needed. Furthermore, the “elements” for inclusive health research requires a more consultative process, where shared thinking and common agreement among humanitarian researchers and human rights actors can be produced. As such, the criteria in this review represent a living body of work that is likely, over time, to expand in breadth and precision as best practices and case studies in the field are identified.

Notwithstanding this reviews’ exclusion of women (gender), we recognise the invaluable guidance and recommendations for gender-inclusive research in humanitarian settings published by the GWI, including the What Works "Research to Action toolkit", as well as the WRC Practitioner guide and toolkit and Empower Aid toolkit. These documents are beacons for guidance on good research, monitoring and evaluation, and ethics in humanitarian settings, and consider all steps in in the research process.
Together, the documents advocate for a participatory approach to research, recognising local expertise actively engaging with local groups throughout the design, data collection, analysis, and dissemination process (e.g. co-production). The What Works “Research to Action toolkit” is a good example of knowledge translation guidance. Empower Aids is a feminist, participatory action research (PAR) toolkit that recognises women and girls as contextual safeguarding experts, and engages them as coproducers of knowledge, supported to safely take an active role in asking and answering questions about their own lives, and prioritising their needs. The toolkit proactively acknowledges and addresses power imbalances—in this case, between men and women; aid workers and those receiving aid; and researchers and those being researched. These documents also use case studies to demonstrate the practical applications of best practices of gender-inclusive research in conflict-affected settings.
REFERENCES


5 Nind M. The practical wisdom of inclusive research. Qualitative Research, 2017. 17(3); 278-288.


13 (ICRC, 2015: 3).


17 Age and Disability Consortium (2018) Humanitarian inclusion standards for older people and people with disabilities (www.helppage.org/download/5a7ad49b81cf8)


19 Anonymous (2016b) Inclusion charter: five steps to impartial humanitarian response for the most vulnerable (www.inclusioncharter.org)

REFERENCES


23 (IASC 2019: 4)


25 Arbeiter-Samariter-Bund (ASB) Indonesia and the Philippines and ELHRA published a comprehensive guidance document called “Everyone can be involved in research

26 Research for Health in Humanitarian Crises (R2HC) / ELHRA / HI


34 Youth and Young Adult Empowerment. Leadership, and Learning Lab. Toolkit for Remote Inclusive Research. Available at: https://yell.ot.phhp.ufl.edu/research/engaging-in-research-during-emergencies/toolkit-for-remote-inclusive-research/


38 CBM. Humanitarian Hands On Tool. Available at: https://hhot.cbm.org/en/card/assessment


41 Missing millions: Infographic on how older people with disabilities are excluded from humanitarian response Available at: https://www.helpage.org/resources/posters/missing-millions-infographic-on-how-older-people-with-disabilities-are-excluded-from-humanitarian-response-


ANNEX 1: KEY TERMS

The question that remains is: How can academics, researchers, non-governmental organisations (NGOs) and development agencies stimulate and generate research that supports real change towards inclusion? To begin to address this question, the IRC conducted a desk review and gathered technical guidance on how to ethically and equitably conduct research on health issues facing marginalised population groups in conflict and humanitarian settings. The review highlights particular resources that can be consulted, adapted, and applied to humanitarian-based health research as necessary.

ACCOUNTABILITY

Refers to the mutual responsibility of all research team members and partner organisations to use their power and resources ethically and responsibly to put the interests of people and communities they aim to serve at the centre of decision-making. This helps ensure humanitarian actions lead to the best possible outcomes and results for affected communities, while protecting and preserving their rights and dignity and increasing their resilience.

AGE GENDER DIVERSITY APPROACH

Conflict and displacement affect individuals differently, depending on their age, gender, disability, and other characteristics that relate to various dimensions of inequality of risk. The UNHCR’s age, gender and diversity (AGD) policy seeks to ensure all persons of concern (PoC) fully participate in decisions that affect them, and enjoy their rights on an equal footing with others.

COMMUNITY ENGAGEMENT

Includes processes to systematically listen to, engage, and communicate with people and communities to better understand their diverse needs, vulnerabilities, and capacities; to gather, respond to, and act on feedback and input about their priorities and preferences; and to provide safe and equitable access and opportunities to actively participate in decisions that affect their lives.

IMPARTIALITY

Impartiality requires humanitarian action to make no discrimination as to nationality, race, religious beliefs, class, or political opinions. It endeavours to relieve the suffering of individuals, being guided solely by their needs, and to give priority to the most urgent cases of distress.13

INTERSECTIONALITY

Intersectionality is an analytical framework that demonstrates how forms of oppression (such as racism, ageism, sexism, ableism) overlap, defining unique social groups. An intersectional approach assumes that each persons’ identity is associated with age, disability, race and ethnicity, gender, or other identities and we cannot understand their health needs or experiences sufficiently by ignoring how multiple aspects of an identity can increase their risk and vulnerability.
INCLUSIVE RESEARCH

For the purpose of this review, the term inclusive research is operationalised as the meaningful participation of marginal identities or subgroups in all stages of the research process that is meant to benefit them. Inclusive research promotes equity, access, opportunity, and the rights of marginalised groups by removing barriers and facilitating representative and locally-driven research.

EMANCIPATORY RESEARCH

The criteria for emancipatory research includes generating knowledge that can benefit the marginalised people. In emancipatory research, research combats social oppression, people with disabilities have control over resources, and the research process is politicized. Emancipatory research’s focus on political transformation separates it from participatory research, which seeks meaningful change but does not fundamentally seek to transform politics as usual.14

PARTICIPATORY RESEARCH

Effective ‘participation’ of people affected by humanitarian crises puts the needs and interests of those people at the core of humanitarian decision making by actively engaging them throughout decision-making processes. It requires an ongoing dialogue and involving multiple stakeholders in the design, data collection, data analysis, distribution, and application of findings. The ultimate goal of participatory research is to bring about more meaningful change.

PARTICIPATORY ACTION RESEARCH

Participatory Action Research (PAR) is related to both participatory and emancipatory research. The basic goal of PAR is to bring together different actor to work together for social transformation. It typically involves non-experts taking charge in the research process. It has emerged from feminist and antiracist grassroots movements that focus on a more “bottom up approach.”

PARTNERSHIP RESEARCH

Partnerships with representative organisations of marginalised group. All stakeholders must have defined roles to play in the research process.

PERSONS OF CONCERN

Persons of concern denotes the groups or persons who experience exclusion, discrimination, and human rights limitations because of their marginal identity (i.e. age, gender diversity, disability, ethnic status, camp or refugee status).

SOGIESC

People of diverse sexual orientation, gender identity and expression, and sex characteristics (SOGIESC), which includes Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, Asexual (LGBTQIA+) people.
ANNEX 2: LIST OF ORGANISATIONS

1. ACF International Network / Action Contre la Faim (ACF)
2. CBM Global Disability Inclusion (CBM)
3. Coregroup
4. Department for International Development (DFID)
5. Enhancing Learning and Research for Humanitarian Assistance (ELRHA)
6. HelpAge International
7. Humanitarian Innovation Fund (HIF)
8. Humanitarian Practice Network (HPN)
9. humanitarianlibrary.org
10. Humanity & Inclusion (HI)
11. Inter-Agency Standing Committee (IASC)
12. Inter-Agency Working Group on Reproduction Health in Crises (IAWG)
13. International Alert
14. International Committee of the Red Cross (ICRC)
15. International Organization for Migration (IOM)
16. International Rescue Committee (IRC)
17. International Planned Parenthood Federation (IPPF)
18. Islamic Relief Worldwide
19. Overseas Development Institute (ODI)
20. Reproductive Health Response in Crisis Consortium (RHRC)
21. Research for Health in Humanitarian Crises (R2HC)
22. Resilience library
23. Results for Development (R4D)
24. Save The Children (STC)
25. Steering Committee for Humanitarian Response (SCHR)
26. U.S. Agency for International Development (USAID)
27. United Kingdom Agency for International Development (UKAID)
28. United Nations High Commissioner for Refugees (UNHCR)
29. United Nations Population Fund (UNFPA)
30. Women’s Refugee Commission (WRC)
### ANNEX 3: EVIDENCE TABLE

<table>
<thead>
<tr>
<th>#</th>
<th>Organisation</th>
<th>General/ groups specific</th>
<th>Type of document</th>
<th>Document name/ description and link to resource</th>
<th>Target audience</th>
<th>Inclusive elements</th>
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</thead>
</table>
  • Advocates participatory methodologies  
  • Guidance on diversity within research teams  
  • End-user friendly dissemination of research findings |
| 2  | ELRHA/ABS                           | People with disabilities | Practical guidelines | Guidance on what works in participatory research with co-researchers | Humanitarian response practitioners, persons with disabilities and Organisations of Persons with Disabilities (OPDs). | Co-researching in humanitarian settings |
| 3  | R2HC                                | Non-camp-based refugees  | Methodological    | Methodological and research review 2020                                                                   | Researchers and staff                                  | • Collaboration leads to research ideas that serve everyone  
  • Local academic and partner collaboration, joint funding between academic institutions and humanitarian actors  
  • Consider contextual feasibility |
| 4  | Save the Children                   | Adolescents             | Methodology framework | Participatory Action Research Toolkit                                                                           | Staff, consultants and youth facilitators            | • Identify funding  
  • Outreach and recruitment  
  • Staff and community engagement in data collection, analysis, and dissemination  
  • Relevant research topics and tools  
  • Capacity strengthening and training  
  • Safeguarding and protection |
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<th>Inclusive elements</th>
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<tbody>
<tr>
<td>5</td>
<td>ACF</td>
<td>Non-specific</td>
<td>Fieldworker manual</td>
<td>This manual is intended to provide methodological and practical guidance to ACF field workers on how to implement Participatory Capacity and Vulnerability Assessment (PCVA) so as to design and initiate stand-alone or mainstreamed Disaster and Relief Management actions at the community level.</td>
<td>Fieldworkers</td>
<td>Its variety of tools and guiding questions for disaster risk analysis facilitate a participatory process through collaborative learning. It is designed to stimulate dialogue and information sharing between ACF's field workers, community members and local partners.</td>
</tr>
</tbody>
</table>
| 6 | HI           | Disability Inclusion    | General guidelines for the protection and inclusion of injured persons and people with disabilities | Learning toolkit for training on collecting disability data Including an e-learning toolkit | Programmers | • Plan for and collect disaggregated data  
• Training data collectors  
• Action research ensures inclusion |
| 7 | Save the Children | Disability Inclusions | Disability checklist | Provides guidance for the protection of injured persons and persons with disabilities | Programmers and partners | • Non-discrimination  
• Identify, locate, and follow up  
• Include specific questions about disability in all assessments  
• Consult with PWD in decision making and planning  
• Provide accessible information  
• Raise awareness of specific and basic needs for vulnerable groups. |
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<th>Document name/description and link to resource</th>
<th>Target audience</th>
<th>Inclusive elements</th>
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| 8  | IRC          | LGBTQ                  | Recommendations for ethical research and learning with and for LGBTQIA people | Recommendations and guidance | Humanitarian actors, agencies, researchers, programmers | • Any research should be participatory  
• Partnership equity is critical  
• Recognise and value the expertise that LGBTQI people have on their own realities, and elevate their lived experiences  
• Humanitarian organisations must undertake ongoing learning and capacity-sharing processes to ensure they have inclusive and supportive policies to protect and support LGBTQI people, including staff, partners, clients, and research subjects |
| 9  | IRC          | Non-specific            | Standards/protocol for equity research | Airbel Lab’s Equity Research Standards | All Staff | • Acknowledge power differentials when conducting research that can be affected/exacerbated by the research process.  
• Develop locally-driven research agendas  
• Cultivate longer-term research partnerships with people or institutes from the countries or regions where research is being conducted  
• Conduct validation workshops to share findings with partners and co-create meaning and recommendations.  
• Dissemination through co-authorship and co-presenters  
• Adaptation, feedback & bi-directional knowledge production  
• Establish community input sessions and global/national advisory groups to advise the study  
• Share research findings in an accessible format, including back to participants.  
• Collect disaggregated data for intersectional analysis.  
• Pre-analysis plans should include information on how data will be disaggregated and/or assessed for modification within evaluations by identities |
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</table>
• Recognise capabilities of marginal persons.  
• Revise and/or develop humanitarian policies, plans, and guidance to ensure diverse LGBTIQ+ inclusion in responses, including developing indicators for monitoring progress. |
| 11 | HPN          | Disabilities, older age  | various          | Provide a range of guidance for inclusion       | Non-specific | • Integrate global training on the Convention on the Rights of Persons with Disabilities.  
• Promote the use and analysis of sex, age, disability, and diversity data  
• Develop practical tools that help staff in the field implement guidelines and capture feedback  
• Operationalise mainstreaming, participation, accessibility, and reasonable adaptations.  
• Ensure inclusive community engagement, training and capacity building of staff and partner organisations on inclusion.  
• Promote the set-up of supportive, inclusive structures and processes to enable a culture of accountability to communities in all their diversity. |
| 12 | ICRC         | People with disabilities | Self assessment/ monitoring inclusion tool | Help teams promote and engage with inclusion | Programmers | • The tool is built on international frameworks and promotes accessibility and partnerships with OPDs  
• Gives indication on how teams are engaging with inclusion  
• Focuses on budget for inclusion of PWDs in project activities (budget for assistance to attend workshops etc). |
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<th>Target audience</th>
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</table>
| 13 | YELL Lab    | People with disabilities | Toolkit          | Toolkit for remote inclusive research in emergency setting. Specifically aims to guide research with research team members with intellectual disabilities | Research team members | • Accommodations to ensure team can participate  
• Adaptations to use strategies during remote collaboration  
• Accessible resources for team members, such as video directions for frequently used technologies that can be customized  
• Suggestions of free and low-cost technologies for remote collaboration. |
| 14 | ODI & HPG   | Non-specific            | Report and       | Seeks to make sense of the concept of inclusion in humanitarian action, explore how it relates to humanitarian principles and outlines some of the key issues and challenges preventing more inclusive humanitarian action. | Humanitarian agencies, funders, researchers | • Disaggregated data collection and intersectional analysis mainstreamed into existing tools  
• Institutions and NGOs representing marginal identities have narrow mandates and incentives and lack capacity and resources to consider partnerships in humanitarian research and practice  
• Presents how research can support progress towards inclusion |
| 15 | CBM         | People with disabilities & older people | Guidance         | Guidance for inclusive rapid needs assessment in emergency settings | Fieldworkers / researchers, enumerators | • Support and include PoC from the beginning  
• Build assessment teams that include someone with disability experience  
• Sensitize field staff and volunteers on AGD.  
• Conduct interviews with all persons across the age, gender, and disability spectrum.  
• Community engagement with PWD and their families and assistants to inform planning.  
• Establish contacts with OPDs or disability and/ or age specialist organisations to exchange data.  
• Disaggregate data.  
• Protect personal data and ask for consent. |
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<th>Inclusive elements</th>
</tr>
</thead>
</table>
| 16 | CBM            | People with disabilities & older persons | Good practice guide | Guide to ensure inclusive humanitarian programming | Humanitarian actors | Change themes  
• Mainstream inclusion within organisational structure.  
• Collect, analyse, and use sex, age and disability disaggregated data.  
• Integrate inclusion within humanitarian, development, and risk reduction programmes.  
• Address intersections between social identities to embed inclusion within programmes.  
• Develop pool of inclusion champions.  
• Challenge cultural and social attitudes towards older people and PWD.  
• Overcome internal barriers to inclusion.  
• Develop inclusion competency of staff.  
• Engage older people and PWD and their representative organisations. |
| 17 | Help Age Intl  | People with disabilities & older persons | Guidance | Provides both the rationale for and practical suggestions on how to gather information to support an ageing-sensitive analysis of humanitarian needs. | Humanitarian actors carrying out assessments | Claim rights  
• Challenge discrimination  
• Age sensitive analysis and sex-and age and sex disaggregated data and assessments  
• Identify older persons and reduce risks  
• No specific guidance for research planning |
| 18 | Help Age Intl  | People with disabilities & older people | Report | Provides recommendations for inclusion in all stages of response | Humanitarian actors | Strengthen evidence and routinely collect and use data on sex, age, and diversity  
• Identify the specific needs, and capacities of older persons with disabilities.  
• Recognise rights and capabilities.  
• Support local organisation to include them in all stages of the response. |
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<th>#</th>
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<tbody>
<tr>
<td>19</td>
<td>Help Age Intl</td>
<td>People with disabilities &amp; older persons</td>
<td>Guidance</td>
<td>Guidance on training for inclusion in humanitarian programming and response</td>
<td>Humanitarian actors</td>
<td>• Donors should provide more resources to local partners for inclusion initiatives&lt;br&gt;• Build a community of practice across organisations to share learning and resources.&lt;br&gt;• Provide a portal for all inclusion training resources as a 'one stop shop.'&lt;br&gt;• More resources available at a local level&lt;br&gt;• More emphasis on increased humanitarian response and DRR awareness on the part of inclusive organisations.&lt;br&gt;• Assessing the reality of how, and during what phases, Humanitarian Inclusion Standards can be operationalised.&lt;br&gt;• Emphasis on barriers faced by older people and the role of caregivers needed.&lt;br&gt;• Training designed and facilitated by older people and people with disabilities.</td>
</tr>
</tbody>
</table>

<p>| 20 | InterAction &amp; USAID   | LGBTQIA+                        | Roadmap for research | Roadmap for Research aims to help generate evidence to better support the Shelter and Settlements sector as a whole, and ultimately make a real difference in the lives of those affected by humanitarian crises. | Humanitarian researchers &amp; programmers | • Learn from existing research and build international collaborations.&lt;br&gt;• Mixed methods and PAR.&lt;br&gt;• Representation, contextualisation, recognise strengths and capabilities.&lt;br&gt;• Let organisations prioritise needs and perceived risks.&lt;br&gt;• Build capacity of in-country researchers.&lt;br&gt;• Encourage LGBTQIA communities and civil society to be researchers of their own lives and designers and implementors of responses. |</p>
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<th>Target audience</th>
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</tr>
</thead>
</table>
| 21 | WRC          | Refugees engaged in sex work | Guidance note    | To start to engage staff on unmet needs and vulnerabilities of refugees who engage in sex work | Humanitarian actors | - The note sets forth concrete actions for working with refugees engaging in sex work, for the purpose of meeting their immediate health and protection needs; ensuring service provision respects their rights and dignity; ensuring services and programming are evidence-based; and strengthening individuals’ capacities to claim and exercise their rights.  
- Calls for more consultation with sex workers and for collaborative consultations and research with sex workers |
<table>
<thead>
<tr>
<th>Gaps</th>
<th>Recommendations</th>
<th>Who do they apply to?</th>
<th>Reference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guidance for research planning and design</td>
<td>Funders and donors need to outline terms of references that include inclusive research criteria, and ask for research teams to be strategically put together with marginal identities considered (representative researchers).</td>
<td>Donors/funders</td>
<td>HelpAge IRC R2HC STC</td>
</tr>
</tbody>
</table>
| Funding and grants for humanitarian research:  
  - Funding often dictates how “inclusive” research can be. | - There is a need for flexible and adaptable funding sources.  
  - Funding bids and the philosophy of the donor should complement approaches and principles of inclusion.  
  - Curb solicited proposals - more directive research calls, shaped by an inclusive prioritisation exercise conducted with practitioners and researchers, may allow for a greater focus on unsolved questions and longstanding knowledge gaps.  
  - Commit to channelling funding to local partners. | | |
| North South Inequities  
  - Research and evaluation efforts are often driven by academics and donor priorities from the Global North.  
  - Important scientific questions come from places where research is conducted and from groups in the Global South. | - Ensure there is participation from research institutions in the Global South / countries with on-going crisis/conflict.  
  - Include representatives of the groups on research steering committees or other similar committees. | Funders/research institutions | IRC |
<table>
<thead>
<tr>
<th>Gaps</th>
<th>Recommendations</th>
<th>Who do they apply to?</th>
<th>Reference</th>
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<tbody>
<tr>
<td><strong>Guidance for research planning and design</strong></td>
<td></td>
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</tr>
<tr>
<td>Accountability/Audit/Monitor</td>
<td>• Hold research institutions and funders of research accountable to inclusion in health research.</td>
<td>All</td>
<td>IRC Airbel</td>
</tr>
<tr>
<td></td>
<td>• Ensure research stages are evaluated for inclusion</td>
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<td>• Monitor how they are meeting the needs of the most vulnerable populations.</td>
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<td>Inclusion is not yet the norm</td>
<td>• Institutionalise inclusion</td>
<td>All</td>
<td>IRC Airbel</td>
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<td></td>
<td>• Adopt a rights-based approach responsive to human rights of marginal groups and use rights-based language in calls for proposals, protocols, scope of inquiries and reports.</td>
<td>Help Age WRC</td>
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<td></td>
<td>• Foster inclusive attitudes and skills development in local and global research institutions through awareness of human rights and diversity.</td>
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<tr>
<td>Cost</td>
<td>• Studies should do ongoing cost analysis and adaptations to ensure strategies to participation are not draining of budget.</td>
<td>All</td>
<td>IRC ICRC</td>
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<td></td>
<td>• Create pockets of participation where it counts the most.</td>
<td></td>
<td>ELRHA</td>
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<td></td>
<td>• Plan and consult on an inclusive and transparent research budget.</td>
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<td></td>
<td>• Allow for budget adjustments for the provision of reasonable accommodation and targeted outreach and recruitment of marginal researchers and participants.</td>
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<td></td>
<td>• Allocate budget for accommodations, assistance to attend workshops, travel needs, interpreters etc.</td>
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<tr>
<td>Diverse representation of researchers</td>
<td>• Targeted inclusion in research should recruit, hire and build capacities of research teams that reflect the marginal groups in conflict settings (i.e. people representing marginal / intersecting groups have equal opportunities for employment as researchers at institutions and co-researchers).</td>
<td>Donors / research institutions, researchers</td>
<td>IRC Airbel CBM STC R2HC HPN HelpAge ODI</td>
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<tr>
<td>Gaps</td>
<td>Recommendations</td>
<td>Who do they apply to?</td>
<td>Reference</td>
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<tr>
<td>Guidance for research planning and design</td>
<td>Partnership equity</td>
<td>Research institutions, researchers</td>
<td>ELHRA</td>
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<td></td>
<td>• Does the research advocate and facilitate equitable partnerships with local, national, and regional organisations, groups, and networks.</td>
<td>IRC Airbel ICRC ACF Int ODI/HPG HelpAge</td>
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<td></td>
<td>• For effective and impactful research, include local research partners who understand the culture, know the root causes of the challenges and problems, and understand context relevant research questions.</td>
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<td></td>
<td>• Identify the capacities and needs of partners to be included in research, including experience implementing activities that are part of the research. For example, experience collecting data via focus group discussions or interviews.</td>
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<td></td>
<td>• Create pockets of participation/identify opportunities for inclusion in different steps of the research process.</td>
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<td></td>
<td>• Plan an activity on understanding what inclusion means for all partners involved including identifying the benefits.</td>
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<td>• All parties involved determine the changes they want to see through a consensus activity.</td>
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<td></td>
<td>Training co-researchers</td>
<td>Research institutions, researchers</td>
<td>ABS</td>
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<td></td>
<td>• Training on inclusion should be led by researchers representing marginal groups.</td>
<td>IRC YELL Lab IPPF CBM HI</td>
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<td>• Empower research teams through awareness of rights and training skills, empowering via co-researchers.</td>
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<td></td>
<td>• Do not over burden co-researchers with data collection.</td>
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<td></td>
<td>• Create opportunities for participation/inclusion in different steps of the research process.</td>
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<td>• Promote shared team decision making through researcher training and teambuilding.</td>
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<td>• Do mapping exercise with all research team members to understand what value they bring, build bi-directional capacity sharing strategies.</td>
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<td></td>
<td>• Create a monitoring, evaluation and learning framework to monitor the capacity building results of the co-researchers.</td>
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<td>• Identify the role of marginal co-researchers throughout the research process.</td>
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| Plan for results  
Often there is no consideration for an inclusive dissemination strategy | • At the start of any research, plan an inclusive research uptake strategy  
• Identify strategies for research dissemination and opportunities for uptake in discussion with the beneficiaries/end-users. | Research institutions, researchers | IRC, ELHRA |
| Sampling may miss the most marginalised | • Reach the *unreachable* through localised recruitment and strategic outreach by representative organisations. Sampling, collecting, and using age, gender, and diversity/disability-disaggregated data for assessments. | Research institutions, researchers | IRC Airbel and We Know nothing ASB WRC STC OCI HPN |
| **Guidance for data collection / methodological gaps** | | | |
| Limited guidance on the limitations of PAR and the benefits of mixed method approaches. | • Design inclusive methods and methodologies, ethical protocols, and research instruments.  
• Ensure all tools and forms are simple to use and culturally appropriate  
• Identify and plan for adaptations to language in the research.  
• Conduct a methodology design workshop with co-researchers.  
• Test the research tools with persons representing marginalised groups.  
• Identify and plan tool options that are easy for all members of the research team to understand and use. | Research institutions, researchers | IRC ASB/ELHRA Light For the World IPPF ACF HI STC R2HC HelpAge InterAction/USAID |
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<thead>
<tr>
<th>Gaps</th>
<th>Recommendations</th>
<th>Who do they apply to?</th>
<th>Reference</th>
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<tr>
<td>Guidance for data collection / methodological gaps</td>
<td>• Shared learning agenda</td>
<td>Research institutions, researchers</td>
<td>IRC Airbel</td>
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<td></td>
<td>• Develop tools or methods to assist research team members to reflect on and document their experiences and lessons learned throughout the research process. (e.g. using learning diaries).</td>
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<td>ACF International</td>
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<td>• Incorporate the researcher’s positionality/reflexivity into the interpretation of results.</td>
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<td>Reflexivity</td>
<td>Make sure the research allows for a reflective process and aids learning for everyone involved.</td>
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<td>Ethical/do no harm</td>
<td>• Ensure members of the research team or research informants can provide feedback, suggestions, and complaints.</td>
<td>Research institutions, researchers</td>
<td>IRC R2HC STC IPPF</td>
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<td></td>
<td>• Showing you have genuinely worked to incorporate suggestions is key to fostering trust and keeping momentum.</td>
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<td></td>
<td>• Ensure marginalised researchers are safe from discrimination and</td>
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<td></td>
<td>• Ensure research is sensitive to wide range of trauma and intersecting marginalisation.</td>
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<td>• Use feedback mechanisms with researcher and co-researcher experiences in the field.</td>
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<td>• Referral systems/ mentoring/ debriefing must be in place for all research team members.</td>
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<td>• Take action for inclusive informed consent/do no harm, the terms, conditions and impacts of research engagement to not negatively impact research members and groups involved.</td>
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<td></td>
<td>• Oral consent and no lengthy procedures.</td>
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<td></td>
<td>• Institutionalise debriefing and self care for all team members</td>
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<tr>
<td>Feedback</td>
<td>• Research teams must follow up on feedback and complaints from all members during the research process.</td>
<td>Researchers</td>
<td>HPN</td>
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<tr>
<td>Analysis</td>
<td>• Encourage participation in data analysis / group thematic analysis involving multiple stakeholders (including marginalized population) and validation meetings.</td>
<td>Researchers</td>
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<tr>
<td><strong>Guidance for dissemination/uptake</strong></td>
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<tr>
<td>Sustainability</td>
<td>The sustainability of partnerships for inclusive research relies on allyship and advocacy.</td>
<td>Researchers / ROs</td>
<td>IPPF HPN</td>
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<tr>
<td>Potential for local actors and partnerships to develop or sustain this action in the future</td>
<td>• Evaluate and publish results on the effectiveness of inclusive research strategies.</td>
<td>Research institutions/ researchers / ROs</td>
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<td>Lack of outcomes / evidence of what works.</td>
<td>• Information should only be collected if it will be acted upon.</td>
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<tr>
<td>Research translation</td>
<td>• Co-authorship must be shared with participants and partners.</td>
<td>Research institutions/ researchers / ROs</td>
<td>YELL lab IRC Airbel CCGA</td>
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<td>• Advocate for use of findings by co-researchers and their representative organisations to influence aid and apply for funding that prioritises marginal groups health and inclusion.</td>
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<td></td>
<td>• Use strategies to move beyond co-authorship in academic publications to writing for policy.</td>
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<td></td>
<td>• Use different platforms and products and ensure accessible dissemination of tools and guidelines, training manuals, capacity sharing, community activism, local uptake, and resource mobilisation.</td>
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<td>• Translate outputs/ findings into action/innovation.</td>
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<td></td>
<td>• Consider how to best share findings on social media (esp. Twitter and Instagram).</td>
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