

# **The future of disability research in Australia: protocol for a multi-phase research agenda-setting exercise.**

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# The future of disability research in Australia: protocol for a multi-phase research agenda-setting exercise.

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## Abstract

**Background:** For people with disability to live a good life it is essential that funded research in health and social care addresses their interests, meets their needs and fills gaps in our understanding of the impact services, systems and policies may have on them. Decisions about research funding should be based on a clear understanding of the research priorities of people with disability, their supporters and allies, disability researchers, service providers, and policy makers working in the field.

**Objective:** The aim of this protocol is to describe the research design and methods of a large-scale disability research agenda-setting exercise in Australia, conducted in 2021.

**Methods:** The research agenda-setting exercise involves 3 integrated phases of work. In the first phase, a previous Audit of Disability Research in Australia is updated to understand prior research and continuing gaps in the research. Building on this, the second phase involves a consultation with stakeholders: people with disability and their supporters and family members, the disability workforce, services and connected sectors (e.g., ageing, employment, education, housing), academia, and public policy. Data for the second phase will be gathered via: i) a national online survey, ii) a consultation process undertaken through the government and non-government sector, and iii) targeted consultation with Aboriginal and Torres Strait Islander people, children with disabilities and their families, people with cognitive disability, and people with complex communication needs. The last phase involves an online survey to develop a research agenda based on the outcomes of all phases.

**Results:** TBC

**Conclusions:** This multi-method research agenda-setting study will be the first to provide an indication of the areas of health and social research people across the Australian disability community consider should be prioritised in disability research funding decisions. Project results from all phases will be made publicly available through reports, open access journal publications, and easy-read documents.

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## The future of disability research in Australia: protocol for a multi-phase research agenda-setting exercise.

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### Abstract

**Background:** For people with disability to live a good life it is essential that funded research in health and social care addresses their interests, meets their needs and fills gaps in our understanding of the impact services, systems and policies may have on them. Decisions about research funding should be based on a clear understanding of the research priorities of people with disability, their supporters and allies, disability researchers, service providers, and policy makers working in the field.

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**Methods:** The research agenda-setting exercise involves 3 integrated phases of work. In the first phase, a previous Audit of Disability Research in Australia is updated to understand prior research and continuing gaps in the research. Building on this, the second phase involves a consultation with stakeholders: people with disability and their supporters and family members, the disability workforce, services and connected sectors (e.g., ageing, employment, education, housing), academia, and public policy. Data for the second phase will be gathered via: i) a national online survey, ii) a consultation process undertaken through the government and non-government sector, and iii) targeted consultation with Aboriginal and Torres Strait Islander people, children with disabilities and their families, people with cognitive disability, and people with complex communication needs. The last phase involves an online survey to develop a research agenda based on the outcomes of all phases.

**Results:** Work has started on two parts of the research prioritisation exercise. The research mapping exercise identified We identified 1241 journal articles and book chapters (referred to as 'research

papers’) and 225 publicly available reports (referred to as ‘research reports’) produced over the 2018-2020 period. The data collection for the national survey has also been completed. We received 973 fully completed responses to the survey. Analysis of these data is currently underway.

**Conclusions:** This multi-method research agenda-setting study will be the first to provide an indication of the areas of health and social research people across the Australian disability community consider should be prioritised in disability research funding decisions. Project results from all phases will be made publicly available through reports, open access journal publications, and easy-read documents.

**Keywords:** Disability studies, Disabled persons, Disability research, Consumer-driven community-based research, Research priorities, Mixed methods, Research design.

### **Introduction**

Internationally there is an increasing need for targeted disability research to align with the changing nature of disability practices, technologies and policy [1]. In Australia and internationally research is needed to inform the implementation of new disability policies, and changes to disability systems and services [2]. This is particularly salient now, as new disability-related policies, including the National Disability Insurance Scheme (NDIS) and the revised ten-year National Disability Strategy [3] are being implemented at federal, state and territory levels. These new strategies and actions mean that disability services and the people they serve must rapidly and continually adapt to new funding, systems, and service structures [4]. Disability research should 1) create new knowledge, 2) encompass the situations of people with disability to address their needs and the issues that are of importance to them, 3) monitor the implementation of new policies, and 4) examine, inform, and impact policy change [5,6]. Furthermore, with finite funding available to support a growing number of active disability researchers in this sector, research resources need to be allocated and used strategically and effectively, taking into account both current and emerging issues. Existing prioritisation exercises undertaken internationally have been limited in scope and method or conducted only in relation to specific groups or without the participation of people with disability, or other interest groups and therefore do not represent a broad range of voices [7-9].

In 2020, the project team successfully tendered to undertake the research agenda-setting study in a two-stage expression of interest process judged by a selection panel within the National Disability Research Partnership (NDRP), which included senior disability researchers, people with disability, supporters and allies [10]. The project team is a consortium of 31 individuals comprising people with lived experience of disability, family members or other supporters, Aboriginal and Torres Strait Islander people, academic disability researchers, and representatives from non-government organisations (NGOs). A full list of organisations named as part of the tender is in Table 1, below. The team is led by a core project group and administered by the University of Sydney. Members of the consortium work in teams to lead and implement different project phases (see Figure 2). Working groups of interested partners were formed from the broader consortium membership to develop and advise on each project phase.

Table 1. Full list of organisations <b>Consortium organisations</b>	Organisation category
University of Sydney – Centre for Disability Research and Policy and Centre for Disability Studies (project leads)	Academic research
Ability First	Non-government organisation

Australian Association of Special Education	Broad-based association
Australian Federation of Disability Organisations	Peak body
Australian National University Lived Research Unit	Academic research
Autism Awareness Australia	Non-government organisation
Centre for Social Impact National (including University of NSW, Swinburne University, University of Western Australia)	Academic research
Children and young people research group (including Murdoch Children's Research Institute, Monash University, Australian Catholic University)	Academic research
Community Resource Unit	Non-government organisation
Council of Regional Disability Organisations	Peak body
Deaf Victoria Inc. (and Expression Australia)	Non-government organisation
Deakin University	Academic research
Disability Advocacy Network Australia	Peak body
Disability Research Network, The University of Technology Sydney	Academic research
Family Advocacy	Non-government organisation
Inclusion Australia	Non-government organisation
Inclusion Melbourne	Non-government organisation
Kindship	Non-government organisation
Nossal Institute for Global Health, The University of Melbourne	Academic research
Mobility and Accessibility for Children in Australia Inc.	Non-government organisation
Motor Neurone Disease Australia	Non-government organisation
National Disability Services	Non-government organisation
Neurodevelopment Australia	Indigenous-owned research non-profit
Ninti One	Non-government organisation
NSW Council for Intellectual Disability	Non-government organisation
Onemda Research and Innovation Centre	Non-government organisation
Queenslanders with Disability Network	Non-government organisation
Settlement Services International	Non-government organisation
University of Melbourne	Academia
University of Queensland	Academia
Vision Australia	Non-government organisation
Women With Disability Australia	Non-government organisation
Academic advisers: Elizabeth McEntyre, Priscilla Ferazzi, Gerard Goggin.	Academic research

Disability, and disability research, is a broad field encompassing a very large range of sectoral interests, different 'diagnostic' or 'impairment' groups (e.g., spinal cord injury, cerebral palsy, intellectual disability, autism), or situations (e.g., housing, education, employment, health, justice and citizenship). Disability research also has many intersections and overlapping boundaries (e.g., in Australia, Aboriginal and Torres Strait Islander people; gender, ethnic and LGBTQI+ communities).



Similarly, disability policy is expansive and crosses over with areas of concern for the wider community, such as health, housing, education, employment, leisure and technology. As such, any attempt at disability research mapping and agenda-setting must be as broad and inclusive as possible. Audits of Disability Research (2014 and updated in 2017) have mapped the Australian disability research field over the 2000-2017 period [11,12]. These Audit reports have been an important resource used by national and international researchers as well as Australian government and non-government organisations as a resource for identifying what research exists and can be utilised in service and policy development [2,13,14]. However, there has been no previous systems-wide attempt to set a disability research agenda in Australia.

In this context, the aim of this research agenda-setting exercise is to map Australian disability research to date, specifically focusing on progress since prior audits, and identify gaps in the research and areas for further inquiry, so as to inform decisions around the design and funding of disability research programs in Australia.[2] The method and findings may inform the disability sector internationally as other countries move to identify agendas based on the priorities of people with disabilities, their families and supporters. This research is novel and important as there have been no comparable consultation process which spans all states and territories across one nation, that focuses on disability across the life course and encompass the range of disability/impairment types, sectors and disability related issues [8].

## Methods

### *Design*

This multi-stage study involves research mapping, community consultation, and an agenda-setting exercise (see Figure 1). Development of the Research Agenda will occur iteratively throughout the project, in consultation with the consortium partners, with multiple points of translation of research findings to stakeholders in accessible formats as the disability research agenda develops. In addition to consultation with the project consortium members, the project management structure includes a user-centred co-creation panel with people with disability and a First Nations-focused advisory panel, each comprising members of the consortium and others within the broader disability community. These panels are active throughout the project, meeting as needed to provide a focused critical voice to project design and analysis decisions including development of the project outputs and final Research Agenda.

Insert Figure 1 here.

### **Project design and pre-planning (completed September 2020)**

The pre-consultation phase involved the consortium in collectively and iteratively developing the proposal through a series of meetings. An initial consortium was developed from interested individuals and organisations who then invited other potential consortium members to participate, seeking their advice on ways to design the broader consultation to be attentive and responsive to the needs of people with disabilities and the disability community.

### **Phase One: Mapping existing research (data collection completed May 2021)**

The research mapping was designed to (a) determine existing published research and gaps in current research; and (b) identify emerging research priorities based on these gaps. The consortium members who were leading this phase (see Figure 2) applied diverse knowledge and interdisciplinary understandings to question the group's situated knowledge of disability. These multiple perspectives were important for the relevance of the review approach and to be inclusive of all forms of

knowledge to ensure that all views, including non-dominant and traditionally excluded views, were heard.

A specified aim of the Research Agenda was to update the previous Audits of Disability Research with research conducted between 2018-2020. The original Audits utilised a conceptual framework based on eight “domains of everyday life” for people with disability: 1. Community and Civic Participation, 2. Economic Participation, 3. Education, 4. Health and Wellbeing, 5. Housing and the Built Environment, 6. Safety and Security, 7. Social Relationships, and 8. Transport and Communication.[3, 4] These domains were used to restrict the search into these 8 categories and then as a structure for the narrative analysis. The current mapping process did away with these domains as limiters in the search terms as we felt it would restrict the breadth of disability research we were able to include in our reporting.

To locate research in peer reviewed journal articles and books, we systematically searched multiple scientific databases: AMED, Avery, CINAHL, Compendex, Embase, ERIC, Global Health, Medline, PsycINFO, Scopus, Sociological Abstracts, Web of Science Core Collection and Informit (which includes the following databases: A+Education, Ausport, Families & Society Collection, Humanities & Social Sciences Collection, Literature & Culture Collection, Indigenous Australia, AGIS, FAMILY, APAIS, AMI, AusSportMed, Heath & Society Collection, Health Collection, RURAL, Transport Index, ALISA, BUILD, ENGINE, ARCH). This approach was developed with the assistance of a university librarian with experience in systematic reviews. See below for an example of the search strategy adapted for multiple databases.

(disab\* OR handicap\* OR "mental\* retard\*" OR "development\* disabilit\*" OR "intellectual disabilit\*" OR "learning disabilit\*" OR "learning disorder\*" OR "hearing impair\*" OR "vision disorder\*" OR "hearing disorder\*" OR "special needs") OR ("cognitive\* disability\*" OR "communication disorder\*" OR "communication disability\*" OR "neurological disorder\*" OR "brain injury" OR "congenital disorder\*" OR autis\* OR "fragile x" OR "genetic disorder\*") OR ("Cerebral palsy" OR "Spina bifida" OR "neurodivers\*" OR "down syndrome" OR "FragileX syndrome" OR "F\*tal Alcohol" OR "prenatal alcohol exposure" OR "Rett Syndrome") OR ("psych\* disorder\*" OR "psych\* disab\*" OR blind OR "vis\* impair\*" OR "low vision" OR "hearing loss" OR \*mute OR deaf\* OR "sign language" OR Auslan OR "special education\*" OR "hard of hearing" OR "attention deficit" OR "Tourette\*") AND (austral\* OR "new south wales" OR "south austral\*" OR "west\* austral\*" OR "northern territory" OR "australian capital territory" OR queensland\* OR Tasmania OR Victoria))

To identify research from public reports (sometimes called grey literature), web-based searches using the Internet search engine Google.com.au were systematically searched. A base search string was used and *Australia\* disability research filetype:pdf* adapted to the relevant terms described above. A search of partner organisation and other key websites identified by the team was undertaken. Additional reports identified by members of the broader Research Agenda research team and a broader call for missing reports was used to identify eligible publications missed through the structured search (see below). Any reports that did not contain original data (e.g., ‘how to’ guidelines and policy submissions) were excluded from the mapping.

#### *Eligibility criteria for study inclusion*

The integrative review identified qualitative, quantitative and mixed methods studies with no limit on study design, data collection methods used, or study quality using the following criteria:

#### **Inclusion criteria**

- Published between 2011-2020

- Published in English in a peer reviewed journal or published book chapter or as a publicly available report
- A full paper which documented the results of an investigation and/or secondary analysis of existing data reporting the aim of the investigation, method, findings and conclusions and/or recommendations
- At least one aim of the study related to people with disability
- Disability research including Australian participants/topics and reporting results on those participants/topics. This included international comparative studies. ‘Topics’ included in order to capture studies such as those about Australian disability policy, social context and services, where there were no participants
- The conclusions derived from results related to people with disability

### **Exclusion criteria**

- The aims of the paper did not relate to people with disability or disability was mentioned only in passing
- Did not contain original data (e.g., commentaries, viewpoints, editorials, policy documents)
- Disability was acute and/or transient (e.g., rehabilitation from an acute injury such as short-term limb dysfunction after a fracture)
- Research which was primarily lab-based and related to genetics, treatment, diagnosis or cure (e.g., “medical prevention and cure”, surgical or clinical) which did not also consider the broader functioning, disability, health and wellbeing of people with disability
- Not a full paper (e.g., conference abstracts) or not available as full text
- Not written in English

### *Identification and selection of studies*

The titles and abstracts of all studies generated through the combined database searches were uploaded to the systematic review software Covidence ([www.covidence.org](http://www.covidence.org)) and the duplicates removed. Excel was used to manage the research reports. Two team members independently screened all search results against the eligibility criteria at both the abstract and full-text screening phases. Conflicts were resolved by a third reviewer.

The initial list of all relevant papers and reports identified were sent to a large range of disability researchers, NGO partners and government agencies in order to identify any papers missed from the search. The list of papers was sent out via the existing networks of consortium members and project advisory groups, with those who received the list encouraged to send it on through their own networks. Any additional papers identified were then screened according to the method described above.

### *Data analysis*

The data extraction task has been shared by multiple members of the research mapping team based a standardized data extraction form. Extracted information included: title, year of publication, abstract, study population, focal group of participants, main type of disability being discussed, age group, aim of the paper, topic, primary focus, secondary focus, study design, further details, and study funding sources. These areas were developed collaboratively by the project team to ensure mapping of key dimensions of disability research in Australia.

Data extracted were then analysed, integrated, synthesized, and presented both quantitatively (number of papers, domain, age, disability group focus, study design/type of research) and qualitatively Narrative synthesis involved identifying (i) main topics within individual studies and synthesising these across studies, (ii) collective limitations of the research scope and methods used

(e.g. an absence of lived experience-led studies) and knowledge gaps across the studies, and (iii) directions for future research across the studies

### **Phase Two (in progress)**

In this phase stakeholders will be consulted using a range of quantitative and qualitative methods to determine their priorities for research, how they use research, and how future research should be shaped so that it is more useful for potential users.

### Methods of consultation

The three main principles underpinning the consultation are *inclusion*, *flexibility* and *self-determination*. These interlinked principles underpin choices made concerning the research methods and their application. It is important to ensure that there are no barriers to participation in the consultation and this demands flexibility in the approaches used. This includes seeking broad feedback and providing methods and resources which enable people to participate by accommodating their communication and information access needs. Thus a multi-pronged, multi-stage, multi-platform consultation process was designed. Non-government disabled people's organisations and advocacy organisations have the best knowledge of their members and therefore how to consult with them. Therefore, a consultation toolkit was designed for use by organisations conducting their own tailored consultations, with resourcing or research support from the consortium as needed. The final approach to consultation by organisations is determined by the communication preferences and styles of their members, using the consultation toolkit.

### **Data collection**

Three main routes of consultation will be used and adapted as needed in different situations:

- 1) **Data collection administered by advocacy organisations, disabled people's organisations and inclusive research groups.** These groups will conduct consultations with members and stakeholders across Australia, with peak bodies cascading consultation to member organisations. They will utilise the parts of the consultation toolkit most useful to them for collecting information from their constituents. Where requested consortium members can lead consultations on behalf of or with organisations. This is particularly important for small advocacy organisations who may be restricted in terms of resourcing to support a consultation.
- 2) **Data collection via an online national survey.** A national survey has been designed by a subgroup of the consortium, including people with disability and advocacy organisation partners. It has been designed to be as open as possible in scope and collect broad perspectives on how research should be used and the main topics of interest for the following groups:
  - a. People with disability, their supporters and allies
  - b. Researchers involved in disability research
  - c. Service providers, the disability workforce (e.g., disability support workers, health professionals, educators), policy makers, and others working with people with disability (e.g., in housing, transport, employment, the arts, health, or education)
  - d. Anyone who is not otherwise participating in the NGO-focused consultationData collection for the national survey has completed.
- 3) **Data collection with First Nations people** in regional and metropolitan Aboriginal communities coordinated by the Aboriginal-owned research organisation Ninti One. This part of the project is led by Associate Professor John Gilroy, who is a leader of Aboriginal disability scholarship and is a descendant of the Yuin Nation of the NSW South Coast. Consultation will involve an online survey adapted from the national survey. The project has embedded Indigenous Standpoint Theory developed specifically for disability research [15-17].

The consultation has been designed to be adapted to Covid-19 restrictions as it could be conducted online as well as face to face following safety protocols. Furthermore, the partnership is geographically spread so that local consultations can proceed without the need to travel interstate.

### **Sample and recruitment**

Stakeholders include people with disability and their supporters and family members, the disability workforce, services and connected sectors (e.g., ageing, employment, education, housing), academia, and public policy. The proposed sampling strategy is not designed to be representative but rather to reach as many interested people as possible and enable in-depth consultation in relation to their views. The consultation aims to capture the interests of anyone who relates to the concept of disability, rather than using any set definition of inclusion. All partners to the consortium act as a gateway to their respective networks and share the consultation resources throughout these networks by distributing consultation resources and opportunities. Twitter is also used throughout the project to advertise the survey and consultation processes.

### Developing the consultation toolkit

A subgroup of the consortium convened to develop and design the consultation toolkit. Based on discussions across the consortium, data collection templates were prepared, reviewed, and finalised. The aim was to provide a standardised template for the return of aggregated data to the consortium, while enabling the consultation to be flexible and responsive to the communication and information needs for the participating organisations and their members/stakeholders. Organisations were encouraged to use consultation approaches typically used with their stakeholder groups, with interview and focus templates provided as guiding documents. Organisations also had responsibility for obtaining informed voluntary consent following their usual processes. Templates for PIS and consent forms were developed by the research team, approved by ethics, used in consultations lead by consortium and inclusive researchers, and available for organisations if required. Where possible the resources in the consultation toolkit were adapted from existing co-developed resources [18,19]. Beyond the working group, draft resources were reviewed internally within four organisations (Council for Intellectual disability, Inclusion Melbourne, Deaf Victoria, People with Disability Australia) in addition to the consortium's co-creation panel.

### Elements of the consultation toolkit

The final consultation toolkit includes the following resources:

- Easy read information leaflet
- Guidance on how to complete an interview and a focus group, including preparation and facilitation and example questions that could be asked
- Resource tip sheet for organisations with which to find additional information to support consultation (e.g., information on consent and supported decision making)
- Accessible surveys for different audiences, including video supplementation using Auslan (Australian Sign Language) to provide context for the consultation and content and purpose of the survey.
- A 'How' template to be completed and returned by organisations/individuals detailing how the consultation took place, what method was used, who was included, so that the depth and breadth of the consultation could be characterised
- A 'What' template to be completed and returned by organisations/individuals collating the findings from the consultation that could inform the agenda-setting task

The information reported in these standardised templates (the 'How' and 'What' templates) facilitates the process of synthesis by the consortium who go on to bring together the consultation results collected through the different methodologies chosen for individual consultations. The 'How'

template will act as a quality indicator by reporting the extent to which people with disabilities participate in and facilitate the consultations nationally.

#### *Data analysis plan*

Surveys: Quantitative data will be analysed using Stata 11.0 for Windows (StataCorp LP, College Station, TX). Descriptive statistics will be used to summarise the data. Frequencies and proportions will be calculated. Qualitative data from open ended text-based responses will be analysed using a modified thematic analysis which involves an open coding technique (Joffe, 2012).

For analysis of the qualitative data an interpretive approach will be taken in analysing the feedback from each sub-section of participants and strands (consultation, survey, focused data collection). Analysis of the consultation 'what' and 'how' templates will take a combined deductive and inductive approach of thematic analysis with themes and research priorities contextualised by descriptive data with regard to involvement of people with disabilities and the nature of impairment groupings as recorded in the 'How' template [20,21].

The analysis seeks not only to document people's views but develop a deep understanding of the context in which these views have been formulated and the meanings underpinning their perspectives. A report of core findings from each strand will be prepared and shared across the consortium to verify the team's interpretations. Thematic analysis and triangulation of findings across participant groups will be prepared and this will form the basis of the Phase three agenda-setting.

The main output of this consultation phase will be a consultation report which describes in detail the methodology, numbers of people engaged with through the process, and the thematic results of the consultation. Consultation results will be produced in accessible formats including Auslan and easy English, as well as ensuring screen reader accessibility. Additional accessibility needs will be met as requested.

#### **Phase three (not yet started)**

##### **Synthesis and development of the Research Agenda.**

This phase will present to the National Disability Research Partnership a policy- and practice relevant Research Agenda. The Agenda will bring together the priorities identified from each phase of the project. It will provide commentary on the evidence supporting the inclusion of each identified research priority, its utility for progressing policy and practice, advancing rights and enabling flourishing of people with disability.

The third phase was informed with reference to the James Lind Alliance Priority Setting Partnership methodology [22, 23]. This is a detailed co-creation methodology used internationally since 2004 to set research agendas in an equal partnership between lay people, people affected by health conditions, support people and professionals.

Phase three will involve consolidating the evidence from Phases One and Two using thematic consolidation and comparison of findings to create overarching research themes

- a. that have been disproportionately under-researched or not researched at all in the Australian context in the past 10 years
- b. where publications do exist but where findings have not been communicated or translated for use at system, community or individual level (evidence-practice gap)
- c. that are considered to be priorities for future research by non-researchers including

people with disability.

The themes, which are yet to be identified, will be presented in an online survey to stakeholders, including representatives of those groups and individuals who took part in the Phase 2 consultations who indicated their interest in participating in Phase 3. Purposive sampling for participants not represented through this opt-in process will be conducted through the consortium, NGOs, governments and research networks. We aim for between 500-1000 responses altogether which is feasible given the response rate for the Phase 2 survey, which was completed by almost 1000 respondents. The survey will focus on high level research themes and will ask respondents to rank and comment on the importance and applicability of these themes from the perspectives of the:

- **Effectiveness** of research into policy and practice related to each of the themes
- **Enabling factors** identified by research related to each of the themes
- **Experiences** explored in research about everyday life and outcomes for people with disability.

#### Data analysis plan

Survey responses will be analysed using the same quantitative and qualitative data analysis processes used for the Phase Two survey to produce the disability research agenda.

The main output of this final phase will be a report to the funder identifying the research agenda themes.

#### *Public and patient involvement*

People with lived experience of disability and their supporters and allies have been involved in all phases of the project, from the beginning of the development of the tender documents and research plan. The research question underpinning this project concerns what should be prioritised in disability research in Australia. This question was developed by the NDRP which includes people with disability. Within this project consortium, the strategies for data collection, analysis and dissemination have all been developed in partnership with people with disability, including core project team members with disability, family members and supporters.

#### *Ethics*

This project necessitates enhanced ethical review because of the potential vulnerability of participants. Co-production of all aspects of data collection is an important part of the ethical approach. Ethics approval has been gained for the Phase 2 survey and other consultation processes from the University of Sydney Human Research Ethics Committee (2021/175; 2021/318; 2021/443). The Phase 3 survey is currently under ethics consideration. All participants in the research will give written consent to participate in interviews and focus groups. For surveys consent will be by acknowledgement of reading the participant information sheet and submission of survey. Only full survey data (where the participant has fully completed and submitted the survey) will be used. Where individuals (e.g., children and people with very complex intellectual disability) do not have the legal ability to fully consent for themselves their guardians will give consent, but we will also ask for consent from the participants themselves.

## **Results**

The project was launched in October 2020 and data collection has begun in phases one and two. The project is currently in progress. We have completed the research mapping phase and co-designed the consultation documents for dissemination across participating organisations. The national survey has

been completed.

The main project outputs will be 1) full, accessible reports of all stages; and 2) summary documents which explain the Research Agenda in a briefer format. These will be created in several accessible formats. Summary reports will be distributed to the disability community using email and team websites. Social media (e.g., Twitter, Facebook, LinkedIn) will be used to disseminate project outcomes and to gather feedback progressively throughout the project, using the hashtag #AusDisAbilityResearch. Specific research articles will report all phases of the project, including the mapping and consultation phases.

### **Discussion**

Disability research has the potential to radically improve the lives of people with disability if it is targeted to those areas that are priorities for people with disability, service providers, policy makers and others across the disability sector [10, 24]. Currently there is no way of knowing what the nation's disability research priorities are, leading to a reliance on what researchers, government agencies, and funding bodies consider important based on their own domains, or areas of expertise or responsibility. This multi-method research agenda-setting study will provide an indication of what people across the Australian disability community, including people with disability, consider should be prioritised in disability research [25].

Given that research outputs and impacts will ultimately inform structures for research funding priorities (and in turn policy), it is imperative that these outputs and outcomes have validity, confirmability, transferability, and verifiability across the disability community [6,9]. Communication with the disability community and the inclusion of as many voices as possible is essential to the project process. This need has underpinned decisions about the cross-sector consortium and project organisation. It has also underpinned the decision to primarily conduct consultations through NGO partners. Key elements of the research findings will be released throughout the project to engage the disability sector, including people with disability, in the project as it develops and to encourage participation in the consultation.

### **Declarations**

**Acknowledgements:** We would like to acknowledge the rest of our consortium partners and members of our co-design groups who have been involved in developing the project methodology.

**Conflicts of interest:** The authors have no competing interests to declare apart from a general interest in the findings given that the authors are all disability researchers with an interest in the field. Any potential conflicts of interest in the project will be mitigated by the public scrutiny of results and methods as they emerge, along with the collaborative nature of the large research consortium.

**Funding:** This work was funded by the National Disability Research Partnership, hosted by the University of Melbourne and funded by the Department of Social Services through a competitive research process. The funder convened a panel of researchers and consumers to review our application. They are involved in the ongoing project through advertising the project and its outputs. We report timelines and outputs to the funder at regular intervals throughout the project.

**Authors' contributions:** JSM wrote the first draft of the protocol. MAO drafted Phase 2 methodology and AD drafted the Phase 3 section. BH, CI, GC, SD, KE, GG, JG, AG, MM, KM and



JP contributed to the protocol design and edited and shaped the paper further. All authors approved the final version of the paper.

### List of abbreviations

LGBTQI+ Lesbian Gay Bisexual Transgender Queer Intersex plus

NDIS National Disability Insurance Scheme

NGO Non-government organisation

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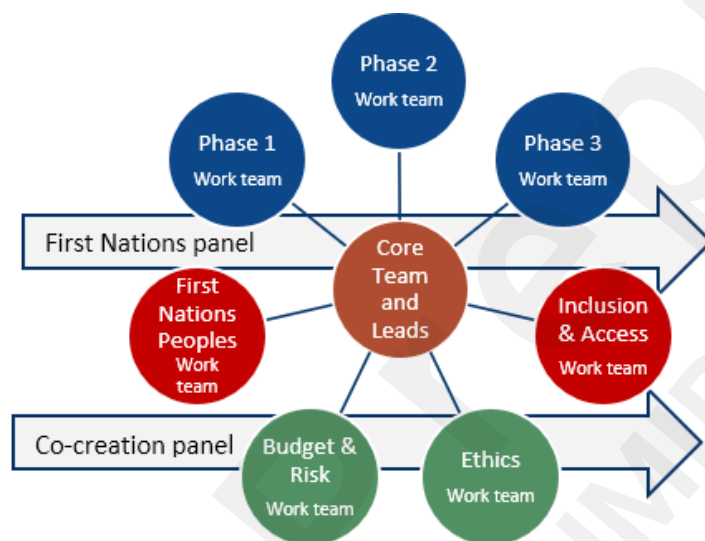
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## Figures and legends

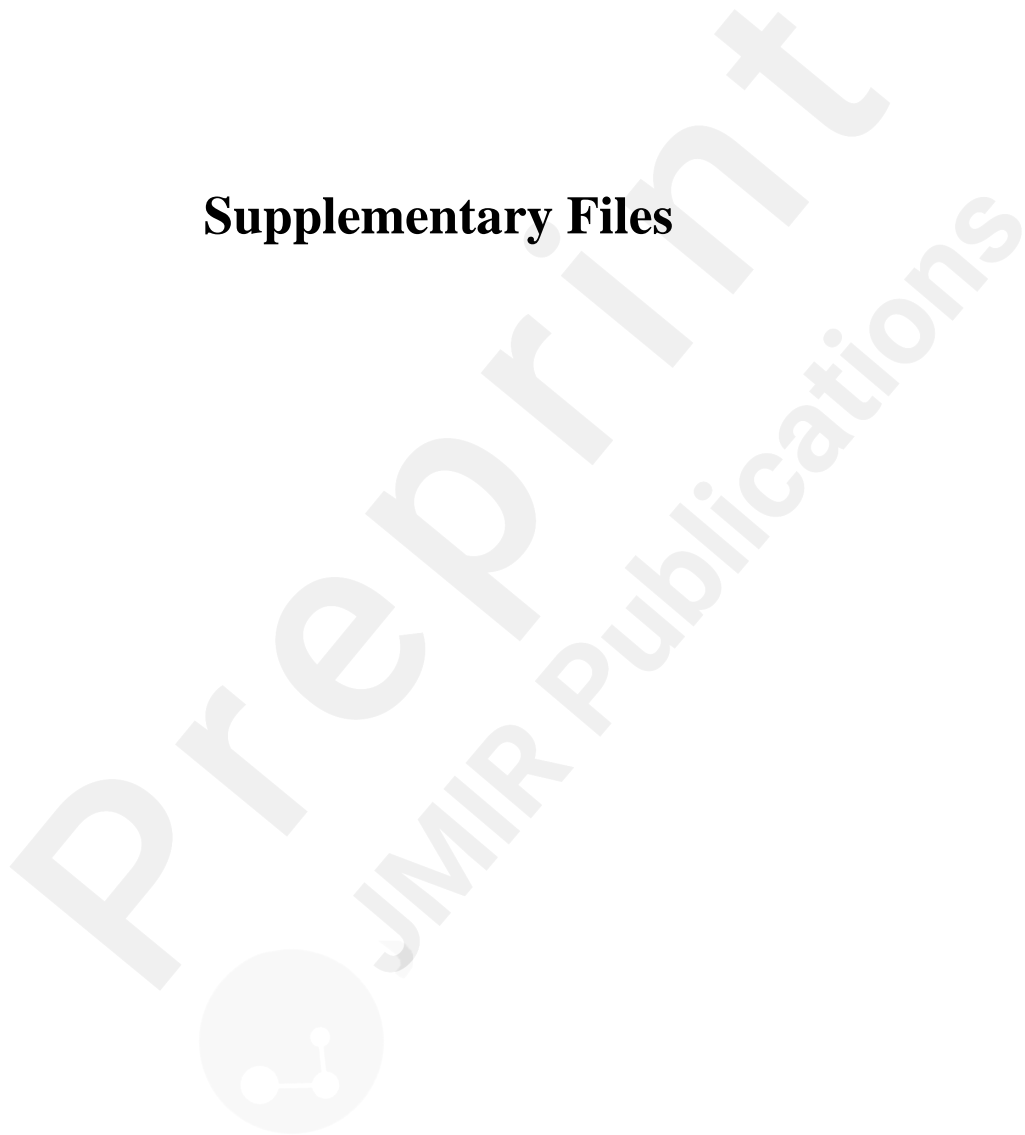
Figure 1 Project design showing the three phases of the project



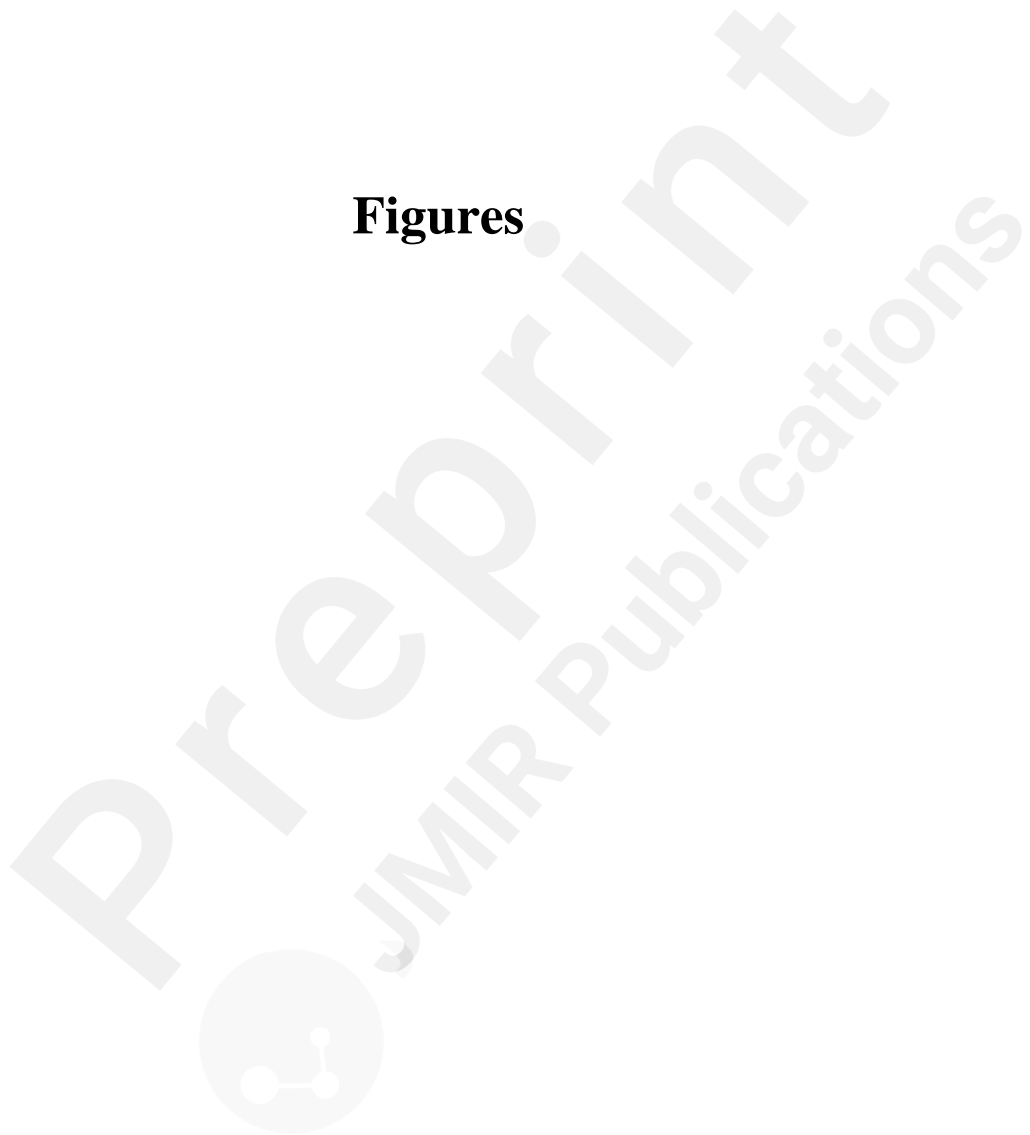
Figure 2 Organisation of Project Phases, Advisory Panels (in red) and teams



## Supplementary Files



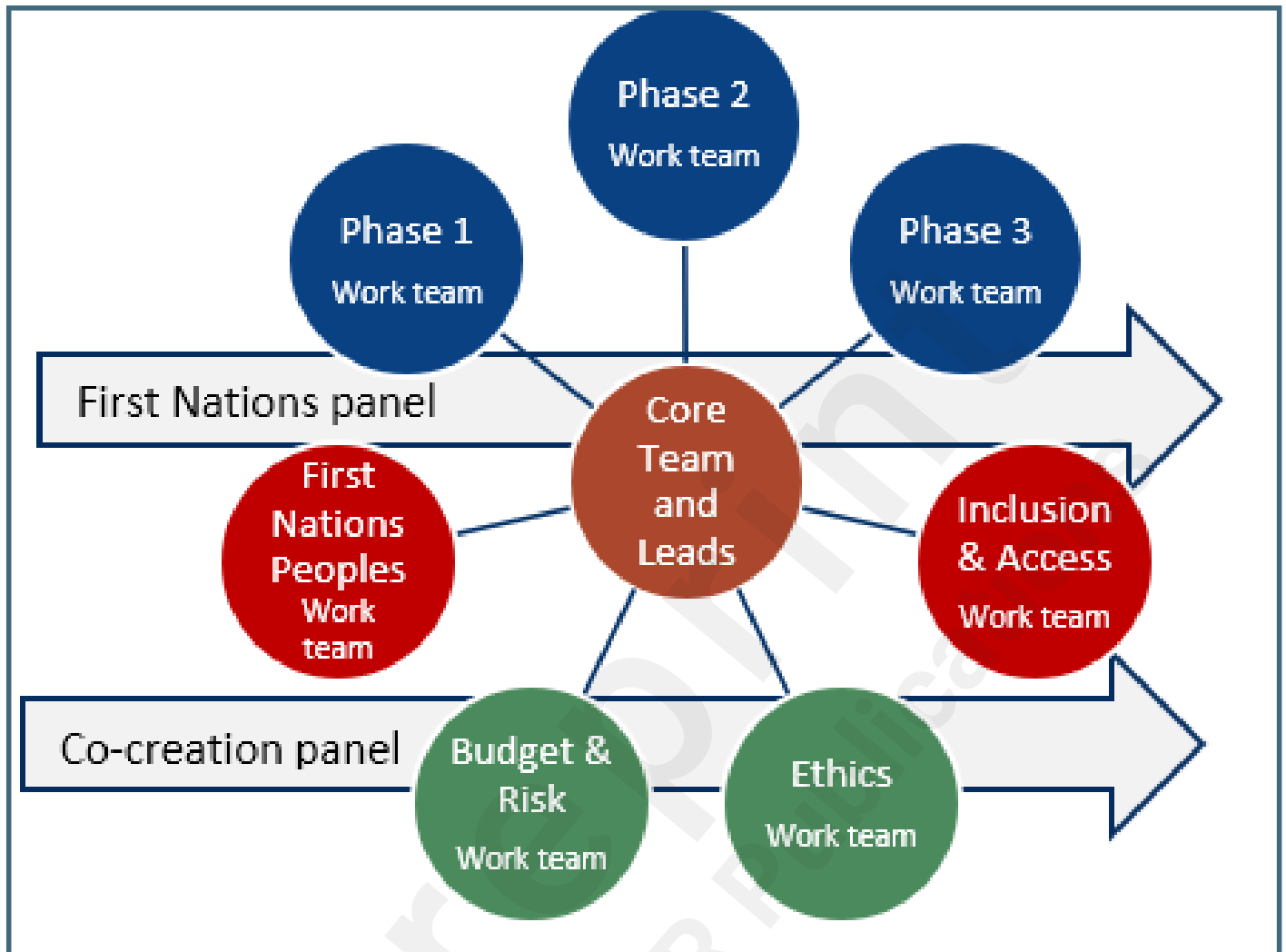
## Figures



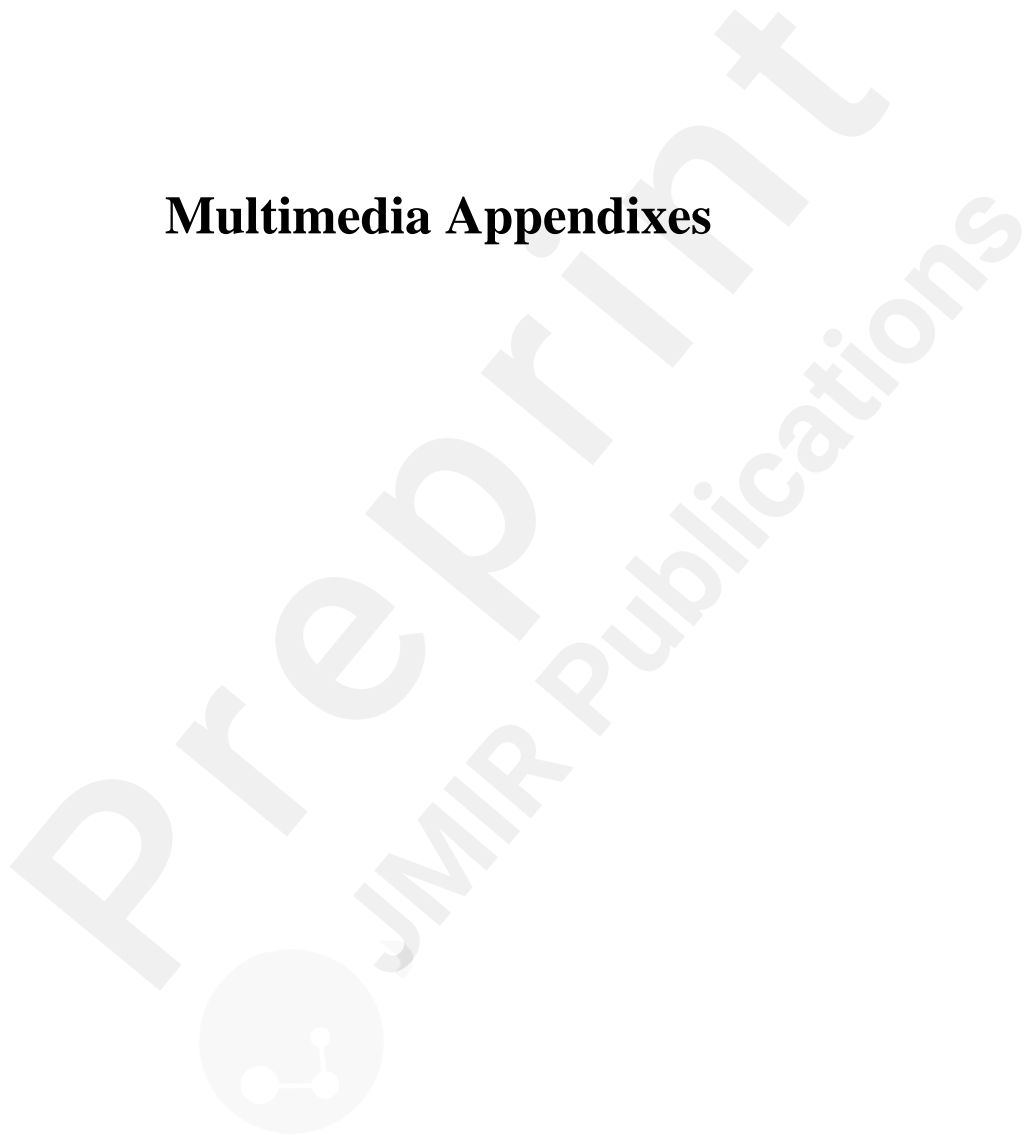
Project design showing the three phases of the project.



Organisation of project phases, advisory panels (in red) and teams.



## Multimedia Appendixes





Data extraction template Covidence.

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## **TOC/Feature image for homepages**

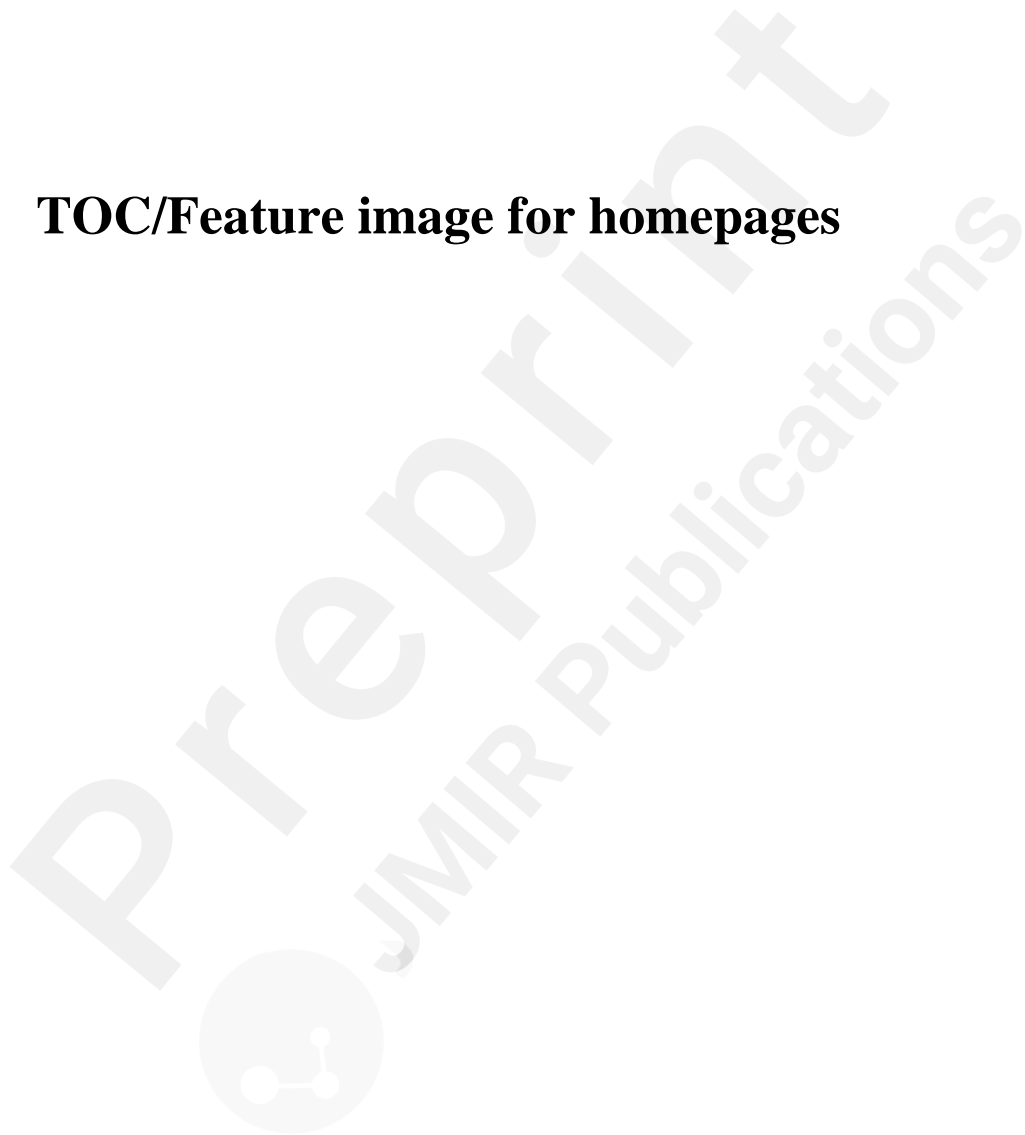


Image for TOC. People holding hands.

