CCNA CCNV

Increasing participant diversity in health research

Literature review and lessons learned from the ENGAGE trial

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Outline

- Introduction: the challenge of recruitment in clinical trials
- Barriers of participation for underrepresented groups
- Facilitators and strategies to improve diversity in research trials
    - Identifying appropriate recruitment approaches
    - Adapting study design and materials
    - Anticipating cost and needed resources
- Implications for practices and resources for researchers

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The challenge of recruitment in clinical trials

- Only **10%** of contacted subjects participate; **1%** for intervention studies (Gul, 2010)

- 40% of trials were **discontinued prematurely** due to difficulties with recruitment; 50% of trials had to be **extended** to enroll a sufficient number of participants; only about 30% of trials **meet their recruitment targets** (Kakumanu, 2019)

- Some subgroups are often **underrepresented**, particularly those groups that would benefit the most from interventions:
  - Minorities and underserved populations have greater health issues (Masood, 2019; McDougall, 2015; Ellard-Gray, 2015; Hughson, 2016; Liljas, 2017)
  - Healthy volunteer bias: Barriers such as poor health can lead to the recruited population not being the intended recipient of the intervention (Nkimbeng, 2020)

Consequences of recruitment issues

- **Scientific**, **economic** and **ethical** consequences (Gul, 2010, Bonevski, 2014; Masood, 2019 ; Hughson, 2016; Liljas, 2017)
  - Decreased **statistical power**
  - **Costs** due to delays for completing the trial
  - Non-representative samples: threats to **external validity** and ability to generalize to the population
  - **Denying excluded groups from any health benefits** of trial participation, and failing to identify groups that have the highest burden of illness and developing an understanding of why differences exist
  - Leads to **more inequities** in health service provisions

ProSymbols, US

Statement

- The US National Institutes of Health (NIH) **Revitalization Act** of 1993 (Public Law 103-43 - https://orwh.od.nih.gov/sites/orwh/files/docs/NIH-Revitalization-Act-1993.pdf)
  - Mandated **more inclusiveness** in government-funded research, specifically for woman and minorities
  - Trials should be designed to permit valid **subgroup analyses**
  - **Cost is not an allowable reason** for excluding minorities
  - Support will be provided for outreach efforts to fulfill this mandate

- Researchers are still in need of more strategies to facilitate greater inclusion in study samples

Terminology…

- **Diverse terminology**: underrepresented, hard-to-reach, vulnerable, socially(socio-economically)-disadvantaged, underserved, hidden, invisible, marginalized, diverse, minorities
- Definitions tend to vary between studies…
  - Sevelius, 2020: **Marginalized** populations include, but are not limited to, groups excluded due to race, gender identity, sexual orientation, age, physical ability, language, and/or immigration status
  - Doherty, 2004:
    - The **minority groups**: the traditionally under-represented groups, the marginalized, disadvantaged or socially excluded
    - The **invisible/overlooked**: those unable to articulate their needs (e.g., those caring for others; those with mental health problems)
    - The **service resistant**: Those unwilling to engage with service providers, the suspicious, distrustful

How are those underrepresented participants?

- Persons who do not engage in health trials often:
  - Are **older** (Anderson, 1995; Blanch, 2008, Carter, 1991; Cooke, 2017; Jancey, 2006; Nkimbeng, 2020; Liljas, 2017; Hussain-Gambles, 2006; Carroll, 2011)
  - Are **men** (Carter, 1991; Cooke, 2017; Graham, 2018; Jancey, 2006; Britten, 2017; but see Bonevski, 2014)
  - **Live farther** from study site (Anderson, 1995; Carter, 1991)
  - Have **lower education** and **lower income/SES** (Blumenthal, 1995; Buys, 2020; Carter, 1991; Cooke, 2017; Crawford, 2010; Gul, 2010; Jancey, 2006; Kammerer, 2019; Bonevski, 2014; Hussain-Gambles, 2006)
    - 1-year increase in education = 9% more likely to participate (Hinton, 2010)
  - Are **ethnic minorities** (Buys, 2020; Cooke, 2017; Bonevski, 2014 ; Hughson, 2016)
  - Are more **isolated**, less involved in the community (Carter, 1991)
  - Have **chronic illnesses** and/or **limited sensory, cognitive, motor abilities** (Crawford, 2010; Kammerer, 2019)
  - Have **lower health awareness** (Gul, 2010)

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Participants' related barriers

- **Health issues** (disabilities, mental health, mobility issues, frailty, fatigue, sensory/cognitive limitations), comorbidities (Anderson, 1995; Carter, 1991; Crawford, 2010; Kammerer, 2019; McHenry, 2012; Mody, 2008; Nicholson, 2015; Piantadosi, 2015; Provencher, 2014; Nkimbeng, 2020; Hughson, 2016; Liljas, 2017; Carroll, 2011; ENGAGE)

- Being a **caregiver** for a relative (Carter, 1991; Kammerer, 2019; McHenry, 2012; ENGAGE) / Taking care of **grandchildren** (Mody, 2008; Liljas, 2017; ENGAGE)

- **Time commitment** (Anderson, 1995; Buys, 2020; Carter, 1991; Crawford, 2010; Dignan, 2011; Ellard-Gray, 2015; Gul, 2010; McHenry, 2012; Piantadosi, 2015; McDougall, 2015; Marsh, 2013; Hughson, 2016; Liljas, 2017; Hussain-Gambles, 2006; ENGAGE)

- **Economic constraints, competing priorities** (Barnett, 2012; Nicholson, 2011; Ellard-Gray, 2015; McDougall, 2015; Hughson, 2016; ENGAGE)

Participants' related barriers

- **Lack of interest/awareness** of health research (Gul, 2010; McHenry, 2012; Kammerer, 2019; Nicholson, 2011, 2015; Bonevski, 2014; UyBico, 2007; Hughson, 2016; Liljas, 2017; Hussain-Gambles, 2006; Otado, 2015; ENGAGE)
- **Lack of perceived benefits** or relevance of study (Provencher, 2014; Mody, 2008; Hughson, 2016; Liljas, 2017; Otado, 2015)
- Fear of **emotional distress** (Gul, 2010)
- Reluctance/difficulties to **change routine** (Gul, 2010; Anderson, 1995; ENGAGE), reluctance of taking additional medication (Piantadosi, 2015)
- **Objection** by a family member (Hinton, 2010; Carter, 1991; Provencher, 2014; Liljas, 2017; Hussain-Gambles, 2006)
- **Transient living situations**; unreliable contact information (Barnett, 2012; Ellard-Gray, 2015); lack of landline phone (Bonevski, 2014)

Participants' related barriers

- **Communication** barriers (Nicholson, 2011)
  - **Language** (Barnett, 2012; Dignan, 2011; Hinton, 2010; McHenry, 2012; Mody, 2008; Nicholson, 2011, 2015; Bonevski, 2014; Kammerer, 2019; Weil, 2017; Ellard-Gray, 2015; UyBico, 2007 ; Hughson, 2016; Liljas, 2017; Hussain-Gambles, 2006; Quay, 2017)
  - **Literacy**:
    - Half the adult population is functionally illiterate above the eighth-grade level (Mody, 2008; Warren-Findlow, 2003; Blanch, 2008 ; Hughson, 2016)
    - Difficulty to cope with length and complexity of study materials, including consent forms, descriptive materials, and testing materials (Mody, 2008; Bonevski, 2014; Piantadosi, 2015; Provencher, 2014)

Participants' related barriers

- **Distrust** of the medical/research community (Barnett, 2012; Buys, 2020; Gul, 2010; Hinton, 2010; Kammerer, 2019; McHenry, 2012; Nicholson, 2011, 2015; Kakumanu, 2019; Nkimbeng, 2020; Provencher, 2014; Mody, 2008; McDougall, 2015; UyBico, 2007; Hughson, 2016)
  - **Negative experiences** as patients/participants (Barnett, 2012; Mody, 2008)
  - **Unfamiliar** with research; fear of abuse and exploitation by researchers (Crawford, 2010; Provencher, 2014; Mody, 2008)
  - Concerns about **safety** (Crawford, 2010; UyBico, 2007; Liljas, 2017); fear of side effects or invasive test procedures (Mody, 2008)
  - Fear of **strangers**/scams (Provencher, 2014; Mody, 2008)
  - Concerns about **confidentiality/privacy** (Ellard-Gray, 2015; Bonevski, 2014; UyBico, 2007; Mody, 2008)
  - Fear of being **pathologized** (Ellard-Gray, 2015)

Contextual/environmental barriers

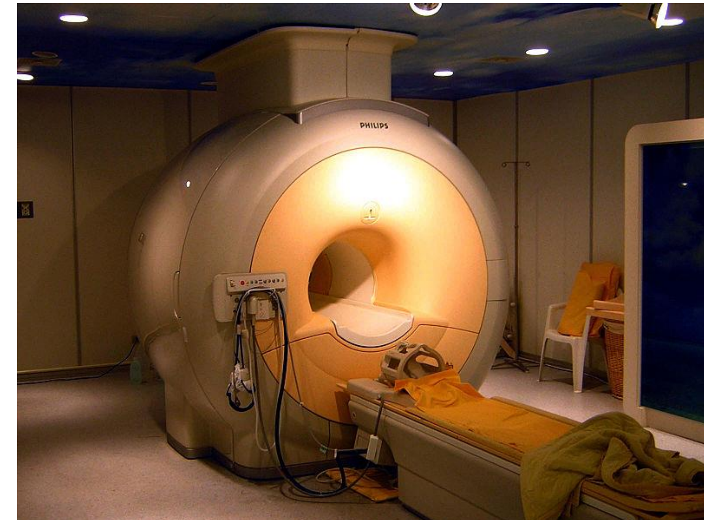
- **Distrust** (collective/cultural level): historical mistreatment, e.g., African Americans (Luebbert, 2016), Indigenous (Bonevski, 2014), Hispanic (Carlson, 2013)
  - **Willingness to participate** is the same in minorities, attitude towards research is positive, problem is just access? (Wendler, 2005)
  - Reputation of research institutions seen as **uncaring** about welfare of minority communities (Mody, 2008; Nicholson, 2015; Hughson, 2016; Otado, 2015; Quay, 2017; Hussain-Gambles, 2006)
  - Perception of research to present **no benefit** to them or their community and may **cause harm** (Bonevski, 2014) or reinforce **stigma** (Sevelius, 2020)
  - Fear of **authority** (immigrants, minorities, marginalized) (Bonevski, 2014)

Contextual/environmental barriers

- **Commute**: distance from study site, lack of transportation, safety of neighborhood (Anderson, 1995; Barnett, 2012; Buys, 2020; Carter, 1991; Gul, 2010; Hinton, 2010; McHenry, 2012; Mody, 2008; Hughson, 2016; ENGAGE)
  - Also true for staff (Blumenthal 1995)
- **Cultural differences**, community practices (Barnett, 2012; Gul, 2010; McHenry, 2012; Bonevski, 2014; Gul, 2010; UyBico, 2007; Hughson, 2016; Liljas, 2017; Hussain-Gambles, 2006; Quay, 2017)
- **Religious practices**/beliefs (Bonevski, 2014; Weil, 2017; Hughson, 2016; Liljas, 2017; Hussain-Gambles, 2006)
- **Objection of physician or 'gatekeeper'** (Carter, 1991; Bonevski, 2014; Weil, 2017; Nicholson, 2011; Carroll, 2011)
  - Paternalistic beliefs that people in lower SES groups don't have time, interest or ability to participate; gatekeepers being very protective of their community members (Bonevski, 2014; Ellard-Gray, 2015; ENGAGE)

Research-related barriers

- Aspects of **study protocol**:
  - Some aspects of the study **design/constraints** – e.g., recording, randomization, etc. (Anderson, 1995; Gul, 2010; McHenry, 2012; Bonevski, 2014; ENGAGE)
  - **Study length**; length and number of sessions (Anderson, 1995; Provencher, 2014; ENGAGE)
  - Demanding or intrusive **assessments** (Provencher, 2014; ENGAGE)



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Research-related barriers

- **Inclusion criteria**:
  - **Strictness** of recruitment criteria (Anderson, 1995; Hinton, 2010; McHenry, 2012; Piantadosi, 2015; Bonevski, 2014; Marsh, 2013; Nicholson, 2015; Clegg, 2015; Carroll, 2011; ENGAGE)
    - Co-morbid medical conditions
    - Education/literacy/language requirements
    - Lifestyle habits
    - Technology literacy/access
  - Problem when participants who could benefit the most from the intervention are not eligible (Kosma, 2004; Nicholson, 2015)
    - Ex., wifi or study partner criteria exclude low SES & lonely individuals (ENGAGE)

  - **Stigmatizing** labeling: people may not identifying themselves as belonging to this population (Ellard-Gray 2015)

Research-related barriers

- **Logistics & resources**:
  - **Limited time and resources** devoted to recruitment (Bonevski, 2014; Ellard-Gray, 2015; Hinton, 2010; Kammerer, 2019; Nicholson, 2011; Piantadosi, 2015; Sevelius, 2020; Provencher, 2014; Carter, 19991; ENGAGE)
    - Non-representativeness of a single recruitment approach (Johnson, 2015, 2020; Martinez, 2006; Bonevski, 2014; Ellard-Gray, 2015; ENGAGE)
  - Research design **doesn't accommodate stakeholder** and service system characteristics (Nicholson, 2011; ENGAGE)
    - Overload of medical staff or organizations in charge of recruitment (Provencher, 2014; Mody, 2008; Bonevski, 2014; Nicholson, 2011)

Barriers are intensified by COVID-19

- COVID-19 => **new** and **intensified** barriers (Sevelius, 2020)
  - Marginalized populations more affected by the pandemic
  - Impact of pandemic on mental health
  - Competing priorities (food insecurity or other increased dangers)
  - Limited privacy to conduct interviews
  - Technological challenges: lack of equipment or computer literacy
  - Difficulty to provide participants' compensation

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Different recruitment strategies

- **Mass mailing** with brochures and/or calls following **random** (e.g., from Federal Electoral Roll), or **quasi-random** (target by postal code, age) sampling
- **Ads** in national, provincial, local **newspapers**, on **TV** or **radio**
- Ads in **social media**; mailing lists
- Participants **registries** (‘banks’)
- Screening from **hospital records**
- Physicians/nurses **referrals**
- Recruitment in **clinics** (waiting rooms)
- **Word-of-mouth**, ‘snowball’, Respondent-driven sampling (RDS)
- **Community outreach**
- **Door-to-door**

Comparison of approaches

- **Most efficient** strategy to get participants **overall**:
  - Releases and media **advertisements** (Anderson, 1995; Piantadosi, 2015; Carrie, 2012; ENGAGE)
  - Mass **mailing** (Jancey, 2006; Marsh, 2013; Lacey, 2017; Westling, 2011; Jancey, 2006; Katula, 2007)
    - Mass mailing can **target** sex, age, race, zip code (targeted list: 2-6% of response; non-targeted: 1%) (Marsh, 2013)
- **But**: Does **not alw** [...] **e** (Arean, 2003; Auster, 2009; McHenry, 2012; Bonevski, 2 [...] 2013)

Comparison of approaches

- **Active recruitment techniques** (in person, face-to-face) seem to **achieve a more representative sample**; more efficient for participants with health conditions or minorities/underserved populations (Cooke, 2017; Gul, 2010; Buys, 2020; Dignan, 2011; Kosma, 2004; Nicholson, 2011, 2015; Arean, 2003; Weil, 2017; Hughson. 2016; Carroll, 2011; but see UyBico, 2007)

  - Home visits & door-to-door work better than flyers and media ads for adults with **low education** (Balmuth, 1988)
  - Face-to-face more efficient than newspaper/TV ads, newsletters and physician referrals for **underserved older adults** (McHenry, 2012)
  - Individual contact better than local ads, media and mailing for **ethnic minorities** (Bonevski, 2014; Auster, 2009)

Comparison of approaches

- **Community-based recruitment** (through trusted community institutions: community centres, senior housing, churches; or in gathering events: health fairs, shopping centres, laundromats, etc.) is often more efficient to reach minorities and special or marginalized populations (Bonevski, 2014; Nicholson, 2015; Weil, 2017; Sevelius, 2020; Carlson, 2014; Provencher, 2014; Arean, 2003; Auster, 2009; Martinez, 2006; Weil, 2017; Blumenthal, 1995; Graham, 2018; Carlson, 2014 but see UyBico, 2007)
  - Especially more efficient to recruit **ethnic minorities** (Masood, 2019; Ellard-Gray, 2015; Blumenthal, 1995; Graham, 2018; Carlson, 2014; Bonevski, 2014; Liljas, 2017; Otado, 2015; Quay, 2017)

Comparison of approaches

- **Word-of-mouth** (Balmuth, 1988; Buys, 2020; Cooke, 2017; Masood, 2019; Hinton, 2010; Bonevski, 2014; Kakumanu, 2019)
  - Especially efficient to recruit **men** (Graham, 2018) and **ethnic minorities** (Liljas, 2017)

- **Respondent-driven sampling** (RDS) (‘**snowball**’) method:
  - Each participant is asked to recruit 3 others, and so forth; incentive (gift card) given for each new participant recruited (Child 2017; Nkimbeng, 2020)
    - Efficient for **minorities** or to improve number of individual from a specific subgroup (Otado, 2015; Ellard-Gray, 2015; Bonevski, 2014)

Comparison of approaches

- **Referrals from clinics/pharmacies/nurses/GP** appeared to be rather **inefficient** in most cases (Hinton, 2010; McHenry, 2012; but see UyBico, 2007)
  - Lack of engagement, not sure of the value of the study, 'gatekeeping' (Chatters 2018; Hughson, 2016; Carroll, 2011)
  - Lack of time/resources (Nicholson, 2011, Bonevski, 2014)

- Only seems to work if:
  - **Thousands** of letters are sent (response rate only 2.3%) (Chatters 2018)
  - **Close collaboration** and frequent follow-up (Balmuth, 1988)
  - Clinics are **paid** for participants they recruit (Kakumanu, 2019)

Comparison of approaches

- **Search medical records** for hard-to-reach participants
  - Not very efficient (Piantadosi, 2015)
  - Efficient if meeting them in person at their medical visits (Barnett, 2012)

- **Social media**
  - May be a good strategy to reach adults (Cooke, 2017) or certain subgroups (LGBT, young, etc.) (Bonevski, 2014)
  - For older adults: technology will become more interesting as the current cohort of younger adults ages (Nkimbeng, 2020)

Comparison of approaches

- **Multiple recruitment methods** will ensure higher diversity (Johnson, 2015, 2020; Martinez, 2006; Bonevski, 2014; Ellard-Gray, 2015; Nkimbeng, 2020; Kakumanu, 2019)
- **Lengthen** recruitment periods (Carter, 1991; Liljas, 2017)
- **Pilot** recruitment (Nicholson, 2011)

Facilitators - contact

- Establish a **friendly rapport** between staff and potential participants (Barnett, 2012; Bonevski, 2014; Kammerer, 2019; Masood, 2019; Singh, 2018; Carroll, 2011; Quay, 2017)
- Avoid stigmatizing **language** (Ellard-Gray, 2015; McDougall, 2015; Hughson. 2016), change terminology of research (e.g., interview instead of assessment) (Bonevski, 2014), use simple language (McHenry, 2012; Hughson. 2016)
- Use colourful, casual **flyers** (McHenry, 2012; Lacey, 2017)
  - Increasing male recruitment by 50% by just changing the brochure picture for an older adult man by himself (Nkimbeng, 2020)
  - Use testimonies to make it sounds like 'word-of-mouth' (Buys, 2020)
- Maintain **repeated contact** with potential participants (Nicholson, 2015; Carlson, 2014; Lacey, 2017; Provencher, 2014; Singh, 2018); keep **staff consistent** (McHenry, 2012; Nicholson, 2011; Carlson, 2014; Mody, 2008; Singh, 2018)
- Ensure having **multiple ways of contacting** participants (Ellard-Gray, 2015; Nicholson, 2011, 2015; Provencher, 2014; Bonevski, 2014; Singh, 2018) and that participants can easily contact research team: toll-free phone number, magnets with study contact info (Ellard-Gray, 2015; Nicholson, 2015; Bonevski, 2014; Singh, 2018; Barnett, 2012)

Facilitators - motivation/incentives

- Providing **incentives** (gift-cards, food baskets, cash, etc.) (Barnett, 2012; Dignan, 2011; Gul, 2010; Hinton, 2010; Kosma, 2004; McHenry, 2012; Nicholson, 2011, 2015; Bonevski, 2014; Lacey, 2017; Mody, 2008; Singh, 2018; Liljas, 2017; Quay, 2017)
  - But does not necessarily attract the more socially deprived people (Chatters, 2018; Bonevski, 2014)
  - More attrition when monetary incentives is the first motivation (Gul, 2010)
  - Selection bias and ethical concerns (coercion) (Provencher, 2014; UyBico, 2007; Hughson. 2016)
  - Watch out for cultural differences (Bonevski, 2014)
- Providing oversight of medical condition, feedback on individual data and referral if needed (Provencher, 2014; Mody, 2008; Lawlor, 2019)
- Appealing to their **altruistic motivations**: contribution to future generations or relevance of research topic to participant's ethnic/age group (Mody, 2008; Provencher, 2014; Kammerer, 2019; Bonevski, 2014; Hughson. 2016; Singh, 2018)

Facilitators - assistance

- Providing or reimbursing **transportation**, offering parking (Dignan, 2011; Ellard-Gray, 2015; Gul, 2010; Hinton, 2010; McHenry, 2012; Masood, 2019; Provencher, 2014; Hughson. 2016; Singh, 2018; Liljas, 2017)

- Or **moving the study to the community**; conducting entire study in natural gathering places (Provencher, 2014; Rich, 2018; Britten, 2017; Manson, 2013; Nkimbeng, 2020; Crawford, 2010; Lawlor, 2019; Rich, 2018)

- Offering **child care** (Ellard-Gray, 2015; Gul, 2010; Hughson. 2016) or **assistance** for participants who are also caregivers (Mody, 2008)

Facilitators - trust

- For **older adults** (Mody, 2008)
  - Work with or establish a **community advisory board** for guidance on community and culturally specific concerns; ensure that study staff understands barriers
  - Introduce the study to the medical community in advance and secure the **endorsement** of physicians whose patients may be targeted for the study, as well as of community leaders, housing, and service agencies
  - Be aware of **scams** that target elderly people
  - Advise **police** in advance if recruiting door-to-door
  - All study staff should have **photo identification**
  - Be ready to communicate and work with a **family member** who feels they need to be involved with study process
  - Provide **continuity** in research staff/contacts
  - Plan for local **dissemination** of study results or other related information of value to the community

Facilitators - trust / cultural sensitivity

- Match characteristics of research staff to the targeted population:
  - **Ethnicity-matching** staff: bilingual and bicultural recruiters; peers to deliver intervention (Blumenthal, 1995; Carter, 1991; Dignan, 2011; Kosma, 2004; Barnett, 2012; Nicholson, 2011, 2015; Bonevski, 2014; Carlson, 2014; Masood, 2019; Hinton, 2010; Arean, 2003; Rich, 2018; Hughson. 2016; Singh, 2018; Liljas, 2017; Otado, 2015)
  - **Gender-matching** staff (Masood, 2019)

- Train researchers and staff to **cultural sensitivity** (Nicholson, 2011, Bonevski, 2014; Carlson, 2014; Provencher, 2014; Masood, 2019; Arean, 2003; Mody, 2008; Hughson, 2016; Singh, 2018; Hussain-Gambles, 2006; Otado, 2015; Quay, 2017)
  - Ensure culturally sensitive **schedule** and **incentives** (Masood, 2019); use **ethnically relevant topics/pictures** during recruitment process (Carlson, 2014; Hughson. 2016; Singh, 2018)

Facilitators - psychoeducation

- Offering pre-recruitment **education** about study topic (Mody, 2008; Provencher, 2014), or about the important of health promotion research (Kosma, 2004; Hughson. 2016; Sheridan, 2011)
  - Demos/films or information sessions to **dispel negative perceptions** (Carter, 1991; Otado, 2015)
  - Include **testimonies of former participants** (matched with targeted population) (Buys, 2020)
  - **Reassuring** people on **privacy** (Mody, 2008)
  - Educate participants on the need for **randomization** (Bonevski, 2014)

Working *with* the community

- Working with **trusted leaders** in the community to overcome fear/mistrust (family member, long-time physician, community staff, church leaders, credible media)
  - Ex., **partnership** with a local Community Action Agency and their home-delivered meal program (Crawford, 2010): recruitment strategies built with drivers, who would distribute pamphlets, explain the study, and introduce the research person

- **But**: not so easy -> gatekee … n to host recruitment & progra … ealth providers or non-profit org … y, 2005; Probstfield, 2011; Bonevski, 2(… GAGE)

Working *with* the community

- Requires **long-term relationship** with institutions (Crawford, 2010; Mody, 2008; Nicholson, 2011, 2015; Bonevski, 2014; Kosma, 2004; McDougall, 2015; Hughson, 2016)
  - From the **very beginning** of study planning, and even before…
    - Assist in variety of events (setting up chairs, providing assistance for attendees, offering free blood pressure checks for staff/members, personalize approaches with members (McHenry, 2012; Ellard-Gray, 2015; Anderson, 1995; McDougall, 2015; Dignan 2011; Graham, 2018)
  - **After** the study is completed
    - Provide **feedback** and share study **results** (Provencher, 2014; Arean, 2003; McHenry, 2012, Nicholson, 2011, 2015; Bonevski, 2014; Kosma, 2004)
    - Express **gratitude**: hand-written thank you notes, thank you awards, ceremonies (McHenry, 2012, Nicholson, 2011, 2015; Bonevski, 2014)
    - **Continue relationship** with community after study completion (Arean, 2003); Ensure provision of **sustainable programs** beyond the life or the research project (Bonevski, 2014; Rich, 2018)

Working *with* the community

- Requires **consultation** and **collaboration** with institutions
    - Trustworthy, transparent, honest relationships with participants and institutions (Gul, 2010; Ellard-Gray, 2015)
    - **Involve the community** in the process, organise community consultation, advisory groups / focus groups to determine content/schedule of intervention, study design, recruitment strategies, etc. (Gul, 2010; Lawlor, 2019; Mody, 2008; Bonevski, 2014; Kosma, 2004; Ellard-Gray, 2015; Nicholson, 2011; Probstfield, 2011; Arean, 2003; Carlson, 2014; Dignan, 2011; Rich, 2018; Johnson, 2015, 2020; Manson, 2013; Hughson, 2016; Singh, 2018; Otado, 2015)
- Requires **providing resources** to institutions (Mody, 2008; Bonevski, 2014; Nicholson, 2011)
    - Make sure the project doesn't give them extra work load to community or clinics' staff

No one-size-fits-all approach

- **Every culture and minority has its own barriers and concerns** regarding mistrust, stigma and burden -> Different cultures require different strategies (Arean, 2003; Mody, 2008; from Nicholson, 2015; Hinton, 2010; Bonevski, 2014; Kosma, 2004; Baquet, 2006; UyBico, 2007; Singh, 2018)
  - People with **unstable SES who reside in an unsafe area** were best recruited through presentations given in local events, while those with stable SES in safe areas were ok with door-to-door and telephone recruitment (Kosma, 2004)
  - Women with **high BMI and low education** more likely to be recruited with personalized strategies, but women with low BMI and higher education prefer less personalized strategies (mass media) (Kosma, 2004)
  - Local ads, media and mailing works more for white; individual contact better for **minorities** (Bonevski, 2014; Auster, 2009)
  - **Different determinants** to participation identified for **ethnic minorities** vs. individuals of **age 65+** vs. individuals with **low education** vs. individuals with **poor health** (Baquet, 2006)

Evaluating 'community readiness'

- Degree to which a community is aware, willing and prepared to take actions regarding a given issue (Gansefort, 2018)

Table 1. Stages of community readiness.

Stage	Title	Description
1	No awareness	Issue is not generally recognized by the community or leaders as a problem (or it may truly not be an issue).
2	Denial/resistance	At least some community members recognize that it is a concern, but there is little recognition that it might be occurring locally.
3	Vague awareness	Most feel that there is a local concern, but there is no immediate motivation to do anything about it.
4	Preplanning	There is clear recognition that something must be done, and there may even be a group addressing it. However, efforts are not focused or detailed.
5	Preparation	Active leaders begin planning in earnest. Community offers modest support of efforts.
6	Initiation	Enough information is available to justify efforts. Activities are underway.
7	Stabilization	Activities are supported by administrators or community decision makers. Staff are trained and experienced.
8	Confirmation/expansion	Efforts are in place. Community members feel comfortable using services, and they support expansions. Local data are regularly obtained.
9	Community ownership/Professionalization	Detailed and sophisticated knowledge exists about prevalence, causes, and consequences. Effective evaluation guides new directions. Model is applied to other issues.

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Adaptation of study design

- Have **less-rigid** study designs (Hughson, 2016)
- **Alternative study designs**
  - Multiple baseline designs, stepped wedge designs and wait-list control groups, have several conditions where **each provides interventions** that are greater than regular services received (Bonevski, 2014; Carroll, 2011)
    - **Open trial design** increases recruitment by 9.4% and retention by 13.9% compared to a blinded, placebo-controlled randomized design (Lacey, 2017)
  - **Preference trial** with a **comprehensive cohort design** (ENGAGE)

Adaptation of intervention content/schedule

- Intervention **must be appealing** to the targeted population
  - **Tailor** intervention to disadvantaged groups using focus groups before, during and after program delivery (McDougall, 2015; Britten, 2017; Lawlor, 2019; Bonevski, 2014; Manson, 2013; Kosma, 2004)
  - **Group-based** interventions for social bonding (+ possibility of one-on-one) (Carlson, 2014; Bonevski, 2014; Rich, 2018; Kammerer, 2019; Cooke, 2017; Liljas, 2017)
  - Make it **fun** (Mody, 2008; Cooke, 2017)
    - Add leisure activities to make it less 'school-like' (ENGAGE)
    - More hands-on activities (less theory) (Bonevski, 2014)
  - Limit use of **technology** or provide great **support** (Selevius, 2020; ENGAGE)
  - **Reduce** number of sessions / length of intervention (ENGAGE)
  - Adjust schedule to **cultural practices**
    - Take religious festive periods into account (Masood, 2019; ENGAGE)
    - In Canada: avoid Winter and Summer for older adults? (ENGAGE)

Adaptation of inclusion criteria

- **Limit exclusion criteria** (Bonevski, 2014; Lawlor, 2019; Britten, 2017; Carroll, 2011)
  - Try to be as **inclusive** as possible
    - Consider eligibility based on participant's **self-report** (Britten, 2017)
  - Consider allowing **participation to non-eligible individuals**
    - Be inclusive to be accepted the community settings (Britten, 2017; ENGAGE)
    - Keep ineligible member of couple not to lose the eligible spouse (ENGAGE)

Adaptation of study outcomes

- **Outcome measures** to be adapted to the targeted populations
  - **Sensory deficits**: use augmenters/amplifiers, allow written versions of tests if it's easier for hearing impaired individuals; large, bold font for visually impaired; allow to respond verbally if manual dexterity issues; allow extra time (Mody, 2008; Carroll, 2011)
  - Use standardized **translations** of instruments or translate material, use bilingual staff or interpreters (Bonevski, 2014; Johnson, 2015, 2020; Mody, 2008; Carlson, 2014; Masood, 2019; Singh, 2018; Quay, 2017)
  - Testing material should be **culturally adapted** (Masood, 2019)
  - **Pilot** testing measures with targeted population (Bonevski, 2014)
  - **Shorten** assessment (Bonevski, 2014; Barnett, 2012; Lacey, 2017); shorter sessions with frequent **breaks** (Provencher, 2014; Mody, 2008; Liljas, 2017)
  - Remove **MRI** as mandatory (Hinton, 2010)

Adaptation of data collection

- **Flexibility**, maximized **staff access and availability** (Barnett, 2012; Carter, 1991; Ellard-Gray, 2015; Mody, 2008; Nicholson, 2011, 2015; Bonevski, 2014)
  - Flexible **time** and **location** (Gul, 2010; Mody, 2008; Provencher, 2014; Lawlor, 2019; Hughson. 2016; Singh, 2018; Liljas, 2017)
    - Allow interviews on evenings and weekends (Barnett, 2012)
    - Allow interviews in participants' and informants' preferred version: in person (at home, at community centre, clinics before/after appointment), by phone, online (Dignan, 2011; Bonevski, 2014; Selevius, 2020; Johnson, 2015, 2020; Carlson, 2014; Masood, 2019; Hinton, 2010; McHenry, 2012; Mody, 2008; Nicholson, 2011; ENGAGE)
    - Offer **different options** for intervention visits (e.g., several similar intervention sessions per week) (Manson, 2013)

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Adaptation of study material

- Eliminate **literacy barrier** for low-education participants
  - **Simplify reading age**: plain language, short sentences; use "readability" guidelines (Mody, 2008; Bonevski, 2014)
    - Compose material at 6th to 8th grade reading level (Blanch, 2008; Warren-Findlow, 2003)
    - See SMOG index of reading difficulty (Blanch 2008)
    - Health literacy expert to train research staff (Blanch 2008)
- Adapt **consent form**
  - Using simple language and short consent form with large print (Provencher, 2014; Bonevski, 2014; Hughson, 2016)
    - Informal consent increases response by 30% (Lancey, 2017); verbal consent more appropriate for some cultures (Hughson. 2016)
    - Use of multimedia (videos, illustrations) to improve understanding and retention of concepts (Hughson. 2016)

In sum…

- 4-step model of recruitment – TIBaR (Kammerer, 2019)
  - (1) Build up **T**rust: understandable language, big font, for the targeted minorities, free hot-line number, data protection, partner with well-known & trusted institutions (use their logos), use top-down strategy by first addressing stakeholders at the higher organizational levels (e.g. mayor)
  - (2) Offer **I**ncentives: material (reimbursement) or immaterial (opportunity to express oneself, social contact, meaningful contribution, access to information or services, feedback on performance)
  - (3) Identify individual **Ba**rriers: mobility, language, responsibilities as caregiver, preferences (e.g., male or female interviewer), time constraints, etc.
  - (4) Be **R**esponsive: flexibility and use of appropriate resources and measures: flexible scheduling, choice of interview location, offer mobility assistance, reimbursements, interpreters, etc.

  - Very important: requires time, financial resources, flexibility and appropriate staff members (qualified + soft skills) -> must be anticipated

Outline

- Introduction: the challenge of recruitment in clinical trials
- Barriers of participation for underrepresented groups
- Facilitators and strategies to improve diversity in research trials
  - Identifying appropriate recruitment approaches
  - Adapting study design and materials
  - **Anticipating cost and needed resources**
- Implications for practices and resources for researchers

Anticipating costs

- Considerable resources needed to recruit and retain underserved populations: **VERY COSTLY** in time, effort, money (Auster 2009; Arean 2003; McHenry, 2012; Selevius, 2020; Provencher, 2014; Kosma, 2004; Hinton, 2010; Bonevski, 2014; Gul, 2010; Johnson, 2015; Lawlor, 2019; Piantadosi, 2015; Probstfield, 2011; Kakumanu, 2019; Nkimbeng, 2020; Rich, 2018; Marsh, 2013; Buys, 2020; Mody, 2008; Carroll, 2011; ENGAGE)

- Impact on staff's mood; stress (McHenry, 2012; Selevius, 2020; ENGAGE)

- Cost and needed resources have to be anticipated and constantly re-evaluated and readjusted during the recruitment process (Bonevski, 2014; Kakumanu, 2019; Marsh, 2013; Nkimbeng, 2020)

Cost per recruitment strategy

- **Mass mailing** is at **low to moderate cost** ($30-$800/pp) (Westling, 2011; Jancey, 2006; Nkimbeng, 2020; Marsh, 2013; Kakumanu, 2019; Bonevski, 2013; Katula, 2007)

  -> But debate on whether this is efficient or not for minorities

- **Face-to-face, community-based**: **high cost** (possibly >$3,000/pp) but bring more minorities/specific populations (Auster 2009)

- **Media advertisements**: **low to high cost** (possibly >$3,000/pp) and not as efficient for specific populations (Bonevski, 2014)

Cost per recruitment strategy

- **ACCESS study**: Effect of free high-value medications and/or tailored health education program on patient outcomes and health care costs among low income seniors at risk of cardiovascular complications (Kakumanu, 2019)
- 4013 pp, age 65+, income < $50K, 1+ cardiovascular disease
- Cost = CAD**$334,330** (20% of study budget; **includes supplies & services + human resources costs**)
- Initial planning: 12 months (instead of 2.5 years); $20,000; only through pharmacies

Table 3 Summary of participants enrolled and cost breakdown, by recruitment strategy

Recruitment strategy	Number of enrolled N (% of total enrolled, 95% CI)	Total cost ($CAD)	Cost per enrolled $CAD/participant
Health care	1527 (38%, 37-40)	158,600	104
Pharmacies	1217 (30%, 29-32)	154,980	128
Health professionals	310 (7.7%, 6.9-8.6)	3620	12
Paper mail	1358 (34%, 32-35)	106,140	78
Canada Post mail-out (n = 122,000)	198 (4.9%, 4.3-5.7)	39,700	201
Coronary angiogram registry (n = 4780)	630 (16%, 15-17)	17,450	28
Contact after hospital discharge (n = 50,042)	530 (13%, 12-14)	48,990	92
Media	350 (8.7%, 7.9-9.6)	69,550	199
Paid media	85 (2.1%, 1.7-2.6)	68,650	808
Paid radio	13 (0.32%, 0.19-0.55)	11,970	921
Facebook	2 (0.050%, 0.014-0.018)	10,500	5250
Hospital programming channel	8 (0.20%, 0.10-0.39)	10,820	1353
Transit advertising	26 (0.65%, 0.44-0.95)	23,160	891
Print media	36 (0.90%, 0.65-1.2)	12,200	339
Unpaid media	265 (6.6%, 5.9-7.4)	900	3
Seniors outreach	252 (6.3%, 5.6-7.1)	16,640	66
Senior's homes/apartments	74 (1.8%, 1.5-2.3)	9790	132
Senior's aid resources	178 (4.4%, 3.9-5.2)	6850	38
Word of mouth	476 (12%, 11-13)	3400	7
TOTAL	4013	354,330	88

[a]Cost calculated using research assistant salary at approximately $30 CAD/h
[b]Cost calculated using research coordinator salary at approximately $60CAD/h

(Table modified from authors' version)

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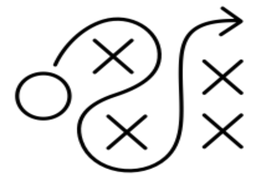
TAKE HOME MESSAGE

- **Multiply recruitment approaches**

- **Know your targeted population; nourish your relationships with the community**

- **Be flexible**



- **Allow sufficient resources and time**

Implications for practices

- Overall, we don't do enough: limited number of strategies were used, lack of tailored approaches and consideration of specific cultural requirements (Masood, 2019)
- **We need help!** Requires a **comprehensive, coordinated, multipronged, long-term** approach involving many strategies across all stages of the research
    - **Support from policy makers, funding agencies and academic institutions** (Bonevski, 2014)
    - **Multidisciplinary work**:
        - Consult with **marketing** and **knowledge translation** experts (McHenry, 2012; Bonevski, 2014; Nkimbeng, 2020)
        - Check **social psychology** principles: Social Practice Theory & Behavioral Change Taxonomy for facilitation of behavioral changes (Lawlor, 2019)
        - Need to develop innovative and cost-effective strategies (Provencher, 2014; UyBico, 2007)

Capacity building with community

- Need more **collaboration** between research/medical institutions and community-based agencies to better connect people with resources (Selevius, 2020)
  - Alzheimer Society of Canada: Community Partnership Coordinator for community building: **Ngozi Iroanyah**
    - Webinar on Tuesday Sept 22nd at 10am: Does Canada provide culturally sensitive dementia care? https://brainhealthsept22.eventbrite.com/
  - Establishment of **research centres** or research collaborations **dedicated to high quality health research with socially disadvantaged groups**: pooling of funding and resourcing, drawing on multidisciplinary expertise, developing registry for interested participants, expansion of partnership networks with community building capacity for future research (Bonevski, 2014)

More transparency in research

- *"In general, academic journals have prioritised the publication of intervention findings above the evaluation and recording of recruitment processes and outcomes. This is limiting because, independent of intervention efficacy, the viability of a program will be determined by its ability to recruit sufficient numbers of eligible participants."* (Cooke, 2017)
- Need more **transparency** in research:
  - **RCTs to document all recruitment strategies** in a separate publication to develop a learning resource for researchers (Masood, 2019)
    - Should indicate: where the population was recruited; who conducted the recruitment; the time spent planning and preparing the recruitment; the time spent conducting the recruitment (Cooke, 2017); the time/cost per recruitment strategy (UyBico, 2007); effectiveness of these strategies on trials outcomes (recruitment of sample size, retention) (Masood, 2019); more info on profile of pp who tend to refuse or drop out (Provencher, 2014)

Web resources

- **Medical Research Council (MCR, UK)**:
  - Guidelines for the development and evaluation of complex interventions: https://mrc.ukri.org/documents/pdf/complex-interventions-guidance/
  - Systematic Techniques for Assisting Recruitment to Trials (START) programme: http://research.bmh.manchester.ac.uk/mrcstart/
- **National Institute of Aging (NIA, US)**:
  - Resource Centers for Minority Aging Research (RCMAR): https://www.nia.nih.gov/research/dbsr/resource-centers-minority-aging-research-rcmar
  - Recruiting Older Adults into Research (ROAR) program: Toolkit & user guide for recruitment material: https://www.nia.nih.gov/health/recruiting-older-adults-research-roar-toolkit
- **National Alzheimer's Project Act (US)**:
  - National Plan to address Alzheimer's disease : https://aspe.hhs.gov/national-plan-address-alzheimers-disease-2014-update

Grants for building relationships with community

- Social Sciences and Humanities Research Council (SSHRC): https://www.sshrc-crsh.gc.ca/funding-financement/programs-programmes/institutional_grants-subventions_institutionnelles-eng.aspx
- New Horizons, Community-based projects for seniors: https://www.canada.ca/en/employment-social-development/programs/new-horizons-seniors.html
- Fonds de Recherche Société et Culture – Québec (FRQSC): http://www.frqsc.gouv.qc.ca/en/bourses-et-subventions/consulter-les-programmes-remplir-une-demande/bourse?id=4fuwuhnz1594398820325&

Join our panel at the CCNA Science Day!

FRIDAY, OCTOBER 16, 2020 – CCNA annual event

12:30 – 2:00 pm EST	**Diversity in dementia research** Facilitators: Aline Moussard, Natasha Rajah

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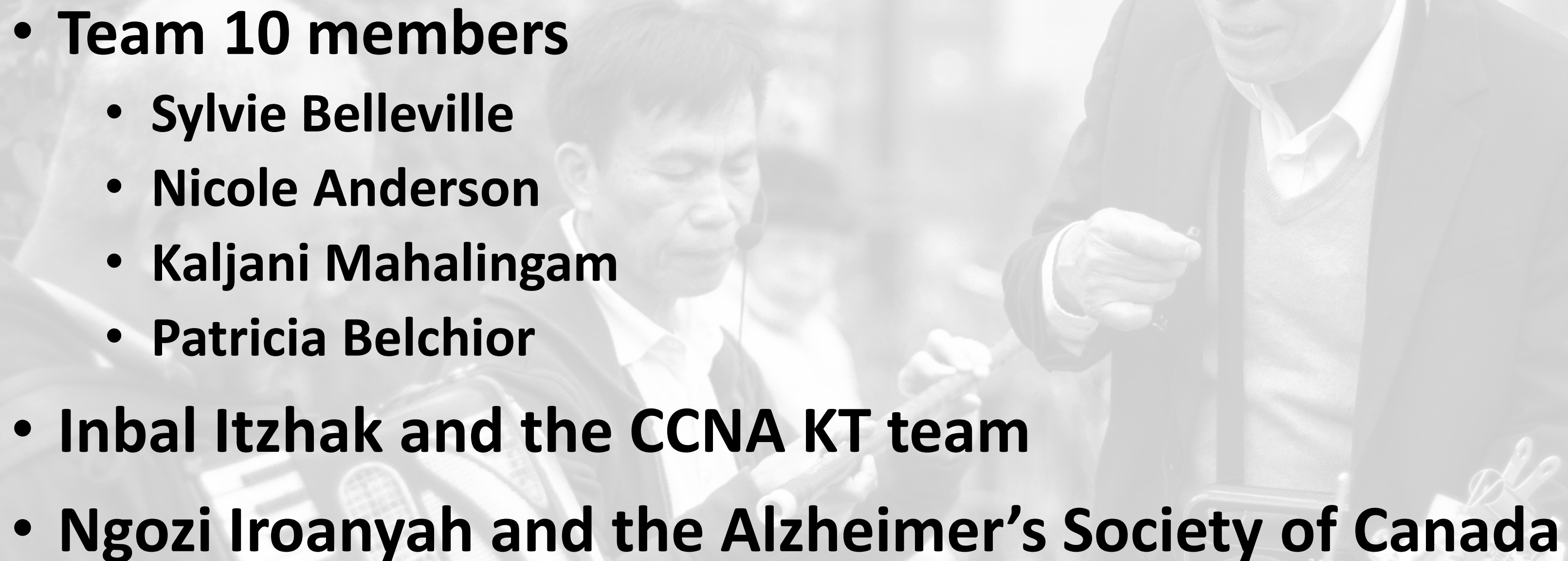

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