



Implementing online psychological support in community settings for young cancer survivors: *A story of evolving partnerships and processes*

Never Stand Still

Medicine

School of Women's & Children's Health

Ursula M. Sansom-Daly, Brittany C. McGill, Pandora Patterson, Annette Beattie, Richard J. Cohn, Claire E. Wakefield.

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Disclosure:

Disclosure: #ImposterSyndrome

I HAVE NO IDEA
WHAT I'M DOING



ILLUSTRATED by
DARIUS FOROUX



A photograph of four people—two men and two women—sitting together and laughing heartily. The man on the far left wears a grey baseball cap and a dark t-shirt. The man next to him is wearing a blue and white jacket. The woman on the far right is wearing a green top. The background is slightly blurred, showing what appears to be a window with vertical blinds.

**The
gap**

**The
plan**

**The
doing
bit**

**The
learning
bit**



**The
gap**

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Changes

NEXT EXIT 

Survivorship mental health care

- AYA years: peak time of onset for mental health disorders
 - 2/2.2x more likely → depr/anx
 - 46% clin distress 10y post

Lang et al. 2018 *Psycho-Oncol.*; Seitz et al 2010 *Eur J Cancer*.

Review Article

Distress and adjustment among adolescents and young adults with cancer: an empirical and conceptual review

Ursula M. Sansom-Daly^{1,2,3}, Claire E. Wakefield^{1,3}

¹Kids Cancer Centre, Sydney Children's Hospital, Randwick, Australia; ²School of Psychology; ³School of Women's and Children's Health, The University of New South Wales, Sydney, Australia

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European Journal of Cancer Care

Original article

Support after the completion of cancer treatment: perspectives of Australian adolescents and their families

C.E. WAKEFIELD, B PSYCH (HONS II, PHD), PROGRAM LEADER, Behavioural Sciences Unit, Centre for Children's Cancer and Blood Disorders, Sydney Children's Hospital (SCH), Randwick, NSW, and School of Women's and Children's

Health Psychology
2012, Vol. 31, No. 3, 380-393

© 2011 American Psychological Association
0278-6133/11/\$12.00 DOI: 10.1037/a0025977

A Systematic Review of Psychological Interventions for Adolescents and Young Adults Living With Chronic Illness

Ursula M. Sansom-Daly
University of New South Wales and Sydney Children's Hospital

Michelle Peate
University of New South Wales

Claire E. Wakefield
Sydney Children's Hospital and University of New South Wales

Richard A. Bryant
University of New South Wales

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Lang et al. 2018 *Psycho-Oncol.*; Seitz et al 2010 *Eur J Cancer*.
- Multi-session, skills-based interventions (e.g., CBT) efficacious (Sansom-Daly et al., 2012)
- Treatment completion: time of risk

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The
gap

Recapture Life: Phase II study

RECAPTURE
LIFE!

- AYAs, **1-12 months** after treatment completion
- Small groups (3-5), psychologist-led videoconferencing
- 6 x 90-minute weekly sessions + booster (+ workbook)



Sansom-Daly et al. *BMC Cancer* 2012, **12**:339
<http://www.biomedcentral.com/1471-2407/12/339>



STUDY PROTOCOL

Open Access

Online group-based cognitive-behavioural therapy for adolescents and young adults after cancer treatment: A multicenter randomised controlled trial of Recapture Life-AYA

Ursula M Sansom-Daly^{1*}, Claire E Wakefield¹, Richard A Bryant², Phyllis Butow³, Susan Sawyer⁴, Pandora Patterson⁵, Antoinette Anazodo⁶, Kate Thompson⁷ and Richard J Cohn¹

Received: 7 June 2018 | Revised: 5 October 2018 | Accepted: 4 November 2018
DOI: 10.1002/pon.4938

PAPER

WILEY

Feasibility, acceptability, and safety of the Recapture Life videoconferencing intervention for adolescent and young adult cancer survivors

Ursula M. Sansom-Daly^{1,2,3} | Claire E. Wakefield^{1,2} | Richard A. Bryant⁴ | Pandora Patterson^{5,6} | Antoinette Anazodo^{2,3} | Phyllis Butow⁷ | Susan M. Sawyer^{8,9,10} | Brittany C. McGill^{1,2} | Holly E. Evans^{1,2} | Richard J. Cohn^{1,2} | The Recapture Life Working Party



"WHAT JUST HAPPENED TO ME?"
(BEING A YOUNG PERSON AFTER (AN)CER)

I'M HOME NOW,
I SHOULD BE SO HAPPY,
SO HOW COME I'M
WAKING UP IN THE MORNING
BAWLING MY EYES OUT?

Recapture Life | 9

I often think that **everyone is looking at me** thinking that something seems odd about me, so I'm **hypersensitive** to those little negative things, so if someone is silent for a bit I'll **start worrying** about what they are thinking.

- AYAs, 1-12 months after treatment completion
- Small groups (3-5), psychologist-led videoconferencing
- 6 x 90-minute weekly sessions + booster (+ workbook)
- 67 participants (45 AYAs 15-25y, 51% female; 19 supports)
 - 5 states, $M=86\text{km}$ from nearest capital city (4-429km)
- 95 sessions conducted, >104 hours total!
- 60 sessions (~90 hours) 'out of office hours'



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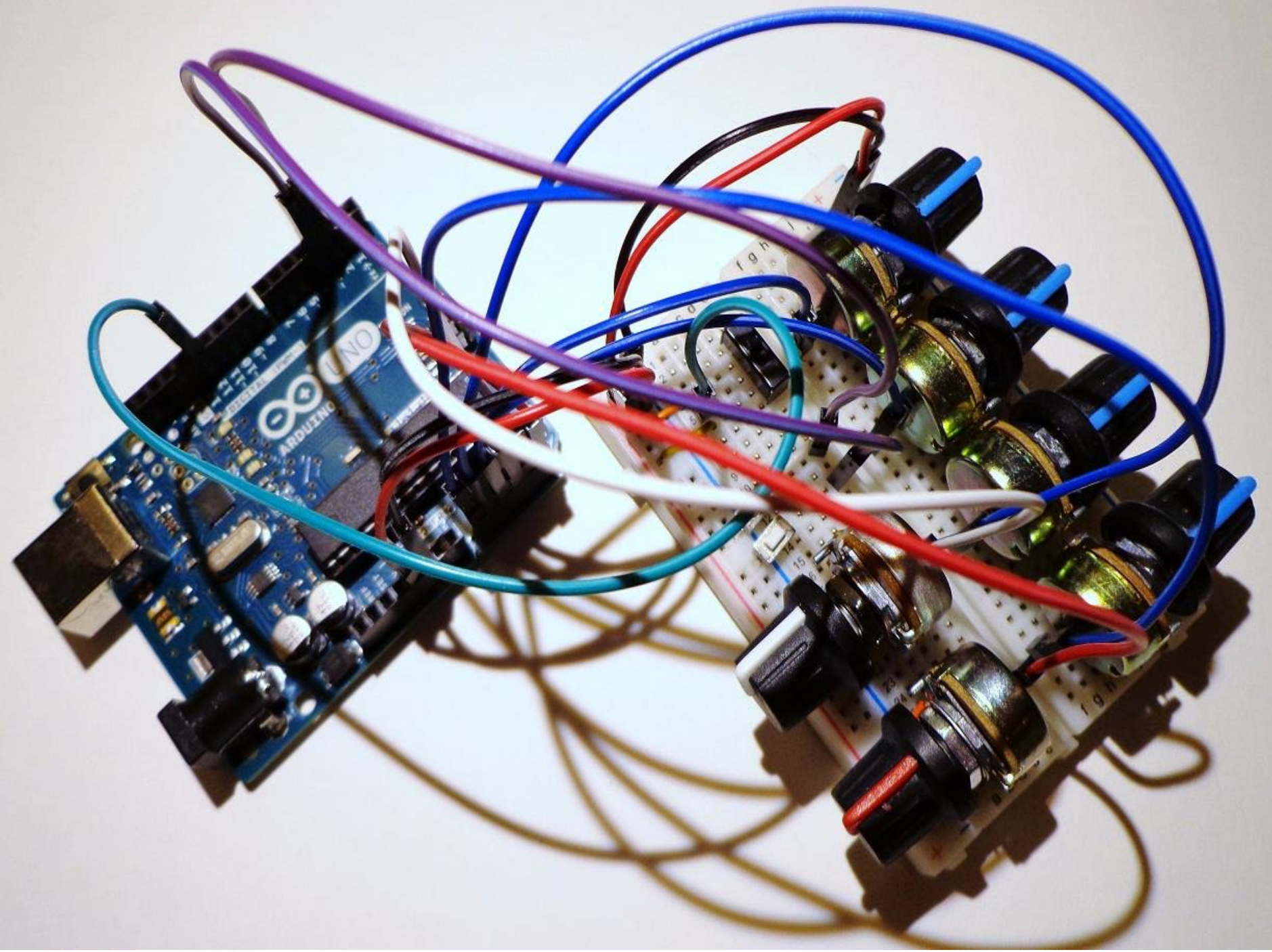
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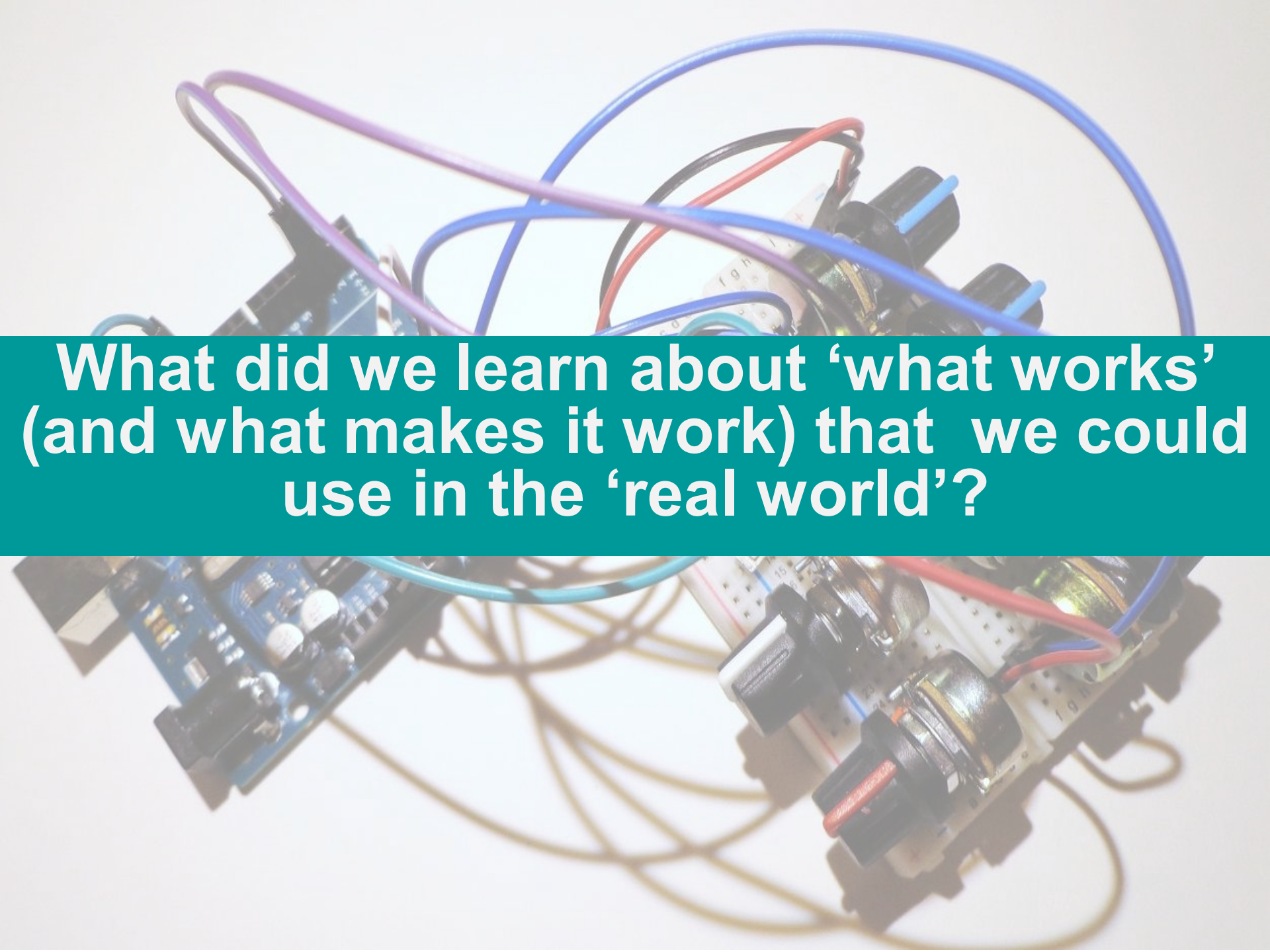
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**What did we learn about ‘what works’
(and what makes it work) that we could
use in the ‘real world’?**

Early implementation data

- AYA openness/responsiveness to online model (*McGill et al., 2017*)
- **Clinician readiness** to run groups? (*Rees & Haythornthwaite, 2004; Sansom-Daly et al., 2015*)
- **Flexibility** needed to run groups – out of hours times
- Manual fidelity/adherence

Australian
Psychologist



ORIGINAL ARTICLE

Ethical and Clinical Challenges Delivering Group-based Cognitive-Behavioural Therapy to Adolescents and Young Adults with Cancer Using Videoconferencing Technology

Ursula M Sansom-Daly,^{1,2,3} Claire E Wakefield,^{1,2} Brittany C McGill,^{1,2} and Pandora Patterson^{4,5}

¹Kids Cancer Centre, Sydney Children's Hospital, ²School of Women's and Children's Health, University of New South Wales, ³Sydney Youth Cancer Service, Prince of Wales/Sydney Children's Hospital, ⁴Research, Evaluation and Social Policy, CanTeen Australia, and ⁵Cancer Nursing Research Unit, Sydney Nursing School, The University of Sydney

JOURNAL OF ADOLESCENT AND YOUNG ADULT ONCOLOGY
Volume 6, Number 4, 2017
© Mary Ann Liebert, Inc.
DOI: 10.1089/jayao.2017.0001

Brief Reports

Therapeutic Alliance and Group Cohesion in an Online Support Program for Adolescent and Young Adult Cancer Survivors: Lessons from "Recapture Life"

Brittany C. McGill, MPsych(Clin),^{1,2,*} Ursula M. Sansom-Daly, PhD,^{1-3,*} Claire E. Wakefield, PhD,^{1,2} Sarah J. Ellis, BAPsych(Hons),^{1,2} Eden G. Robertson, BPsych(Hons),^{1,2} and Richard J. Cohn, MBBS^{1,2}

Workforce capacity + accessibility

- **Lack of capacity in public health system for survivorship work**
 - ~7 hospital-based AYA clinical psychologists nationwide
 - Lengthy process coordinating groups from hospital base

Australian Institute of Health and Welfare, *Mental health services in Australia: in brief 2019*, AIHW, Editor. 219, AIHW: Canberra.



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- **Unknown (lack?) of training in private system (plus \$\$)**
 - 8/10 Australian psychologists currently based in cities (AIHW 2019)
 - Costs can be prohibitive (APS fee: \$260/session; Medicare rebate \$128.40)

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 - Costs can be prohibitive (APS fee: \$260/session; Medicare rebate \$128.40)
- **Unclear/lack of capacity for telehealth in public system***
 - Mental health stigma → trust in community orgs?
 - Greater experience/capacity for online delivery in NGO sector currently

**pre COVID-19!*

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“Will this work?”

+ ALSO

“CAN this work (in the real world)?”

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 - Mental health stigma → trust in community orgs?
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Australian Institute of Health and Welfare, *Mental health services in Australia: in brief 2019*, AIHW, Editor. 219, AIHW: Canberra.

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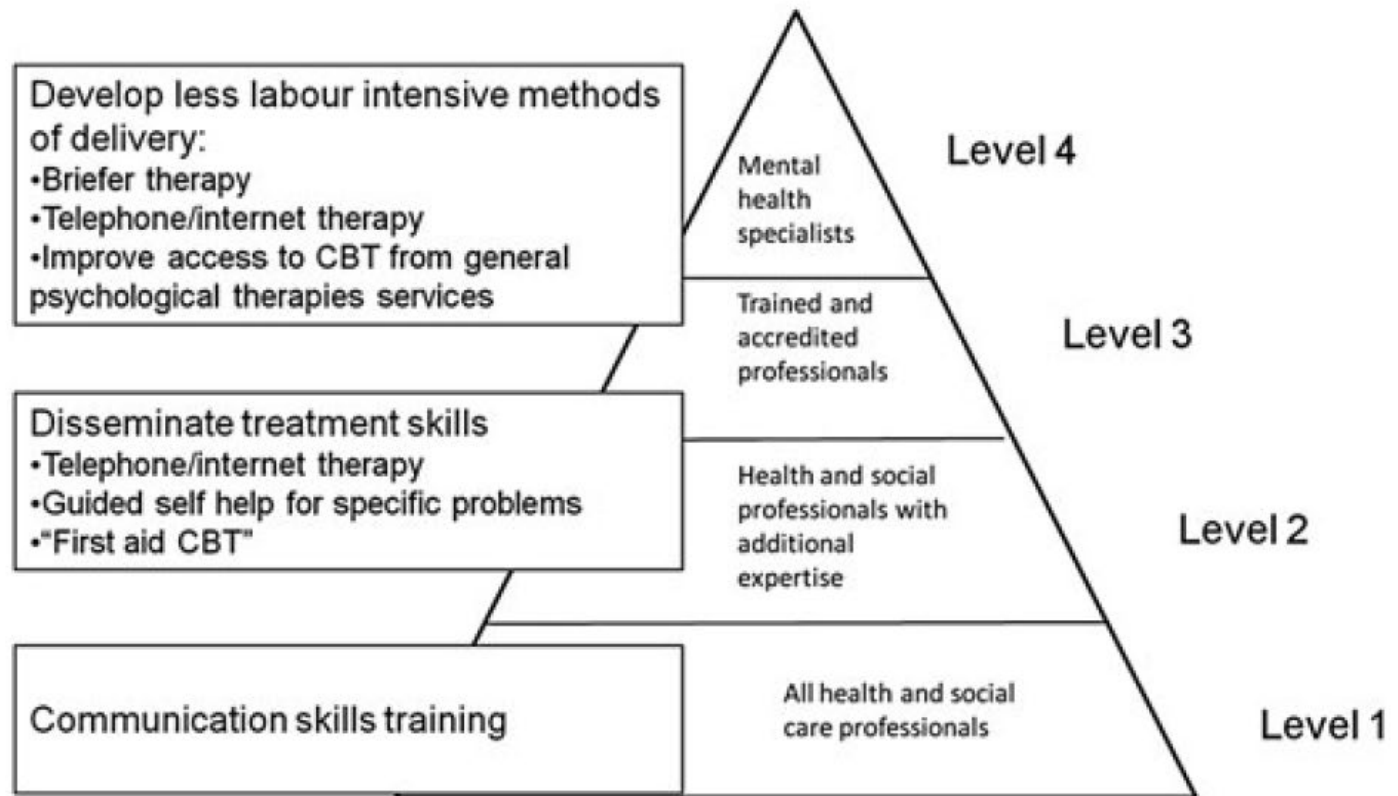


Figure 2. Improving access to psychological help for cancer patients

The
gap

Workforce capacity + accessibility

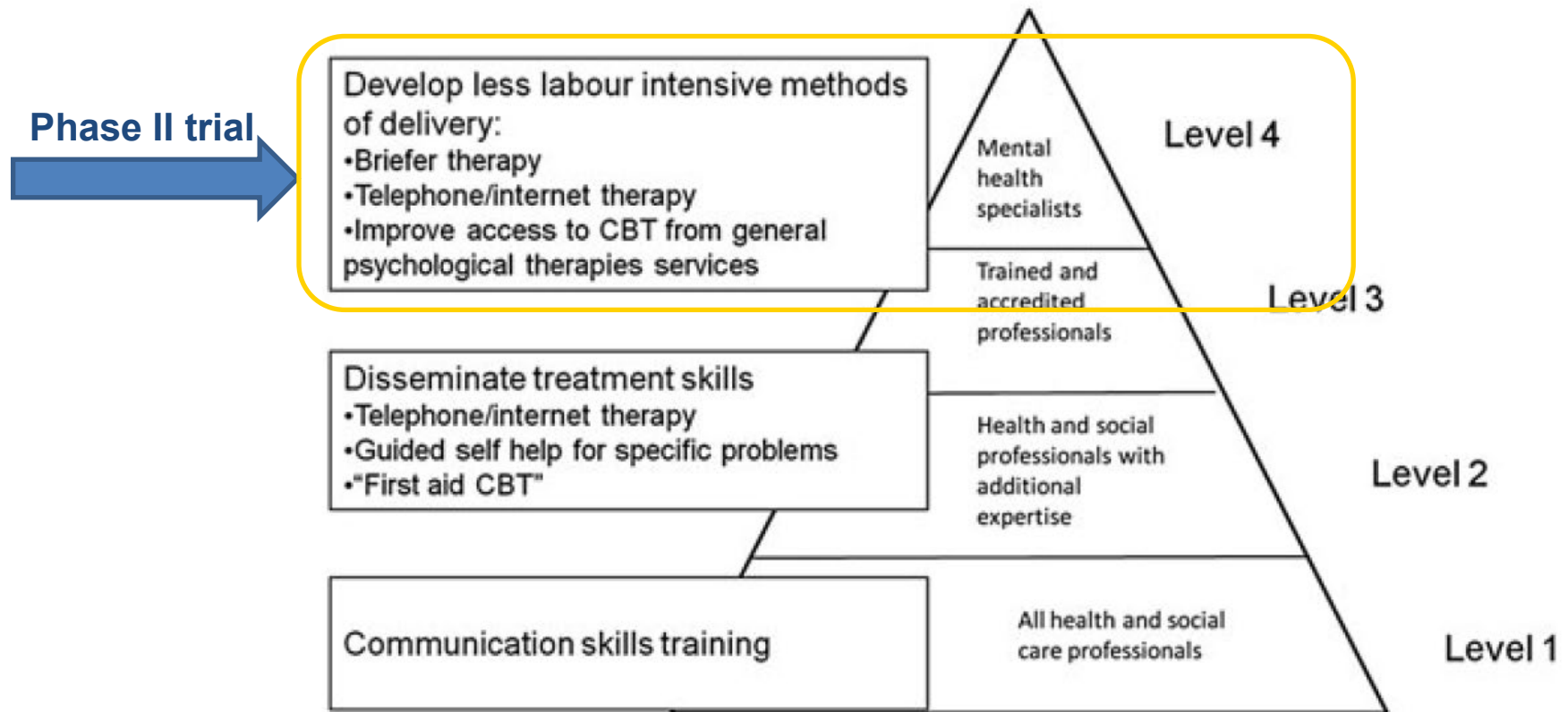


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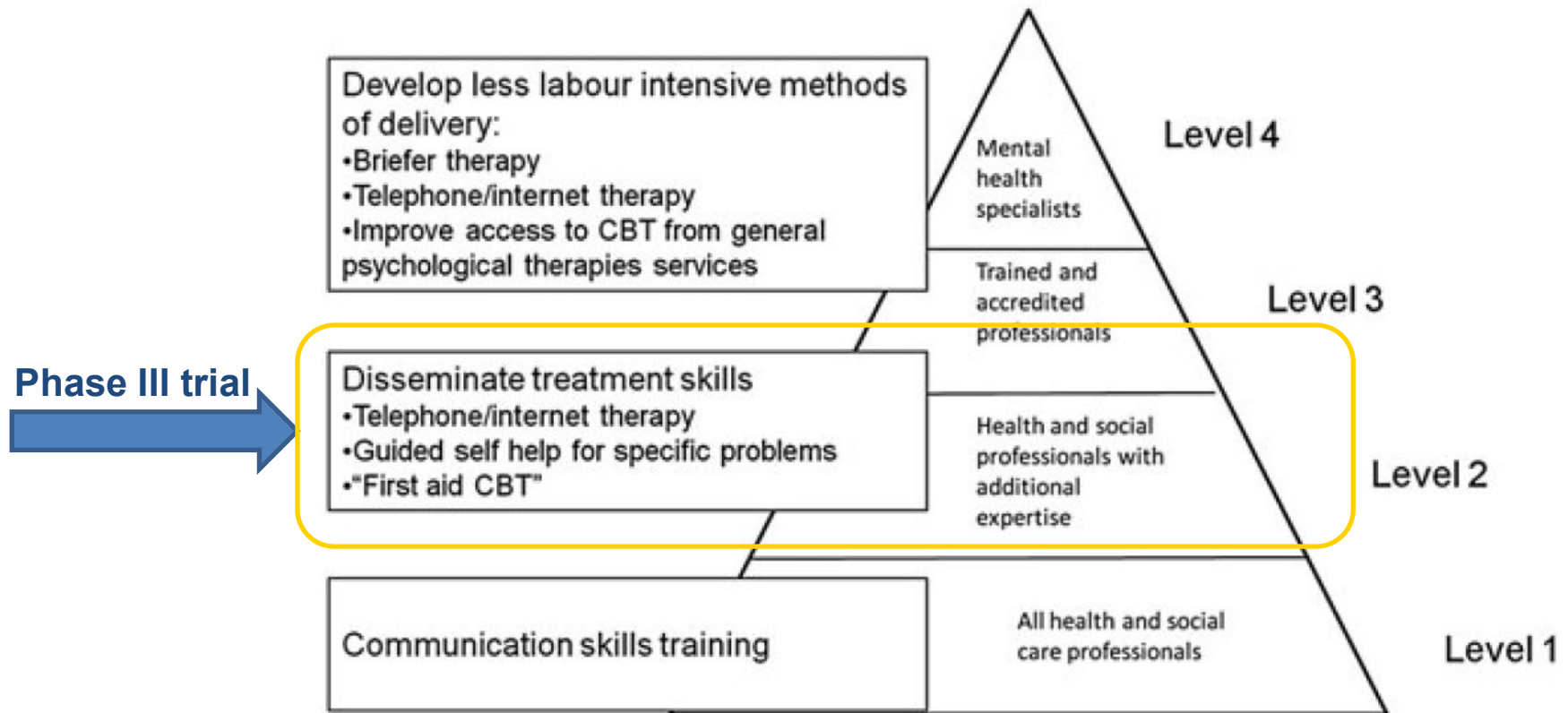


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Community partnerships

Aims: Train community organisations to deliver Recapture Life → assess intervention outcomes in community (feasibility, acceptability, efficacy) and implementation processes (e.g., training up-take, organisational engagement, barriers/facilitators, reach)



Phase III trial design: Hybrid implementation-effectiveness

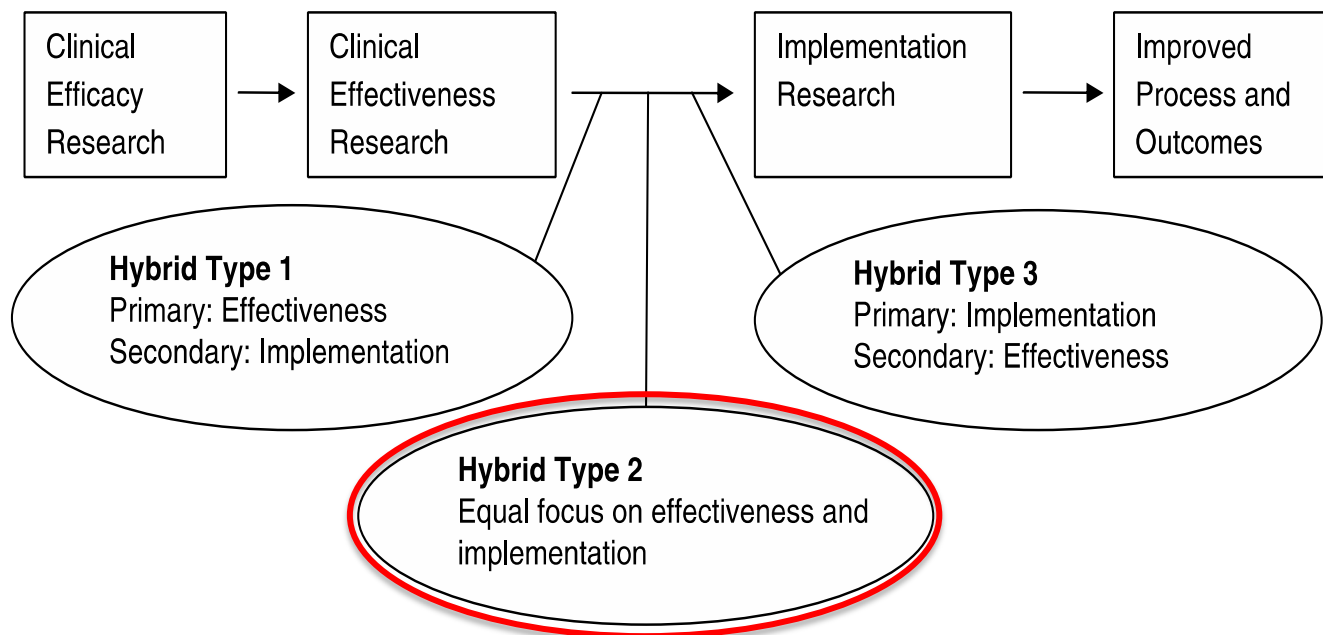


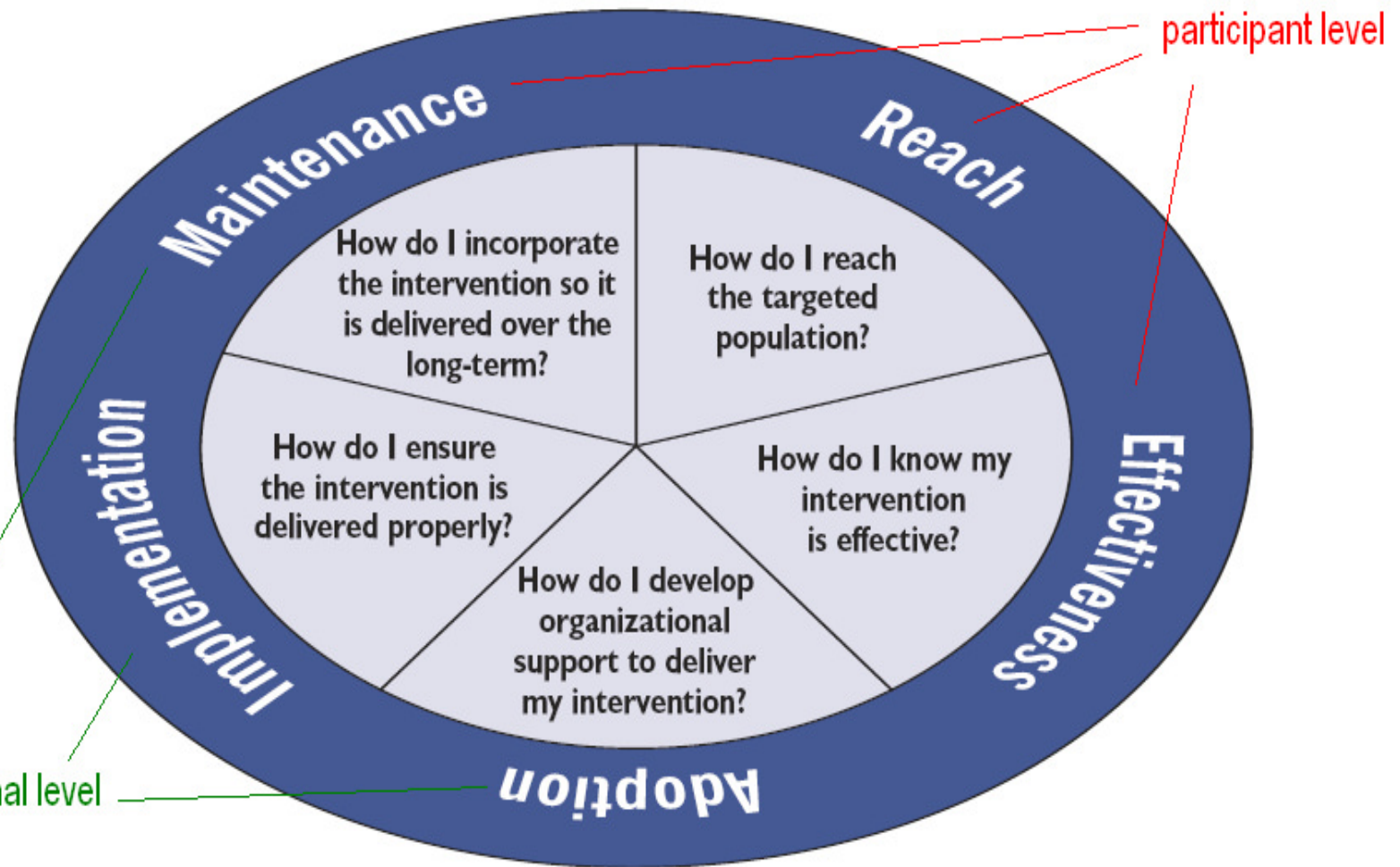
Figure 1 Hybrid effectiveness-implementation designs as part of the clinical research continuum.

From Cully et al, 2012, *Implementation Science*

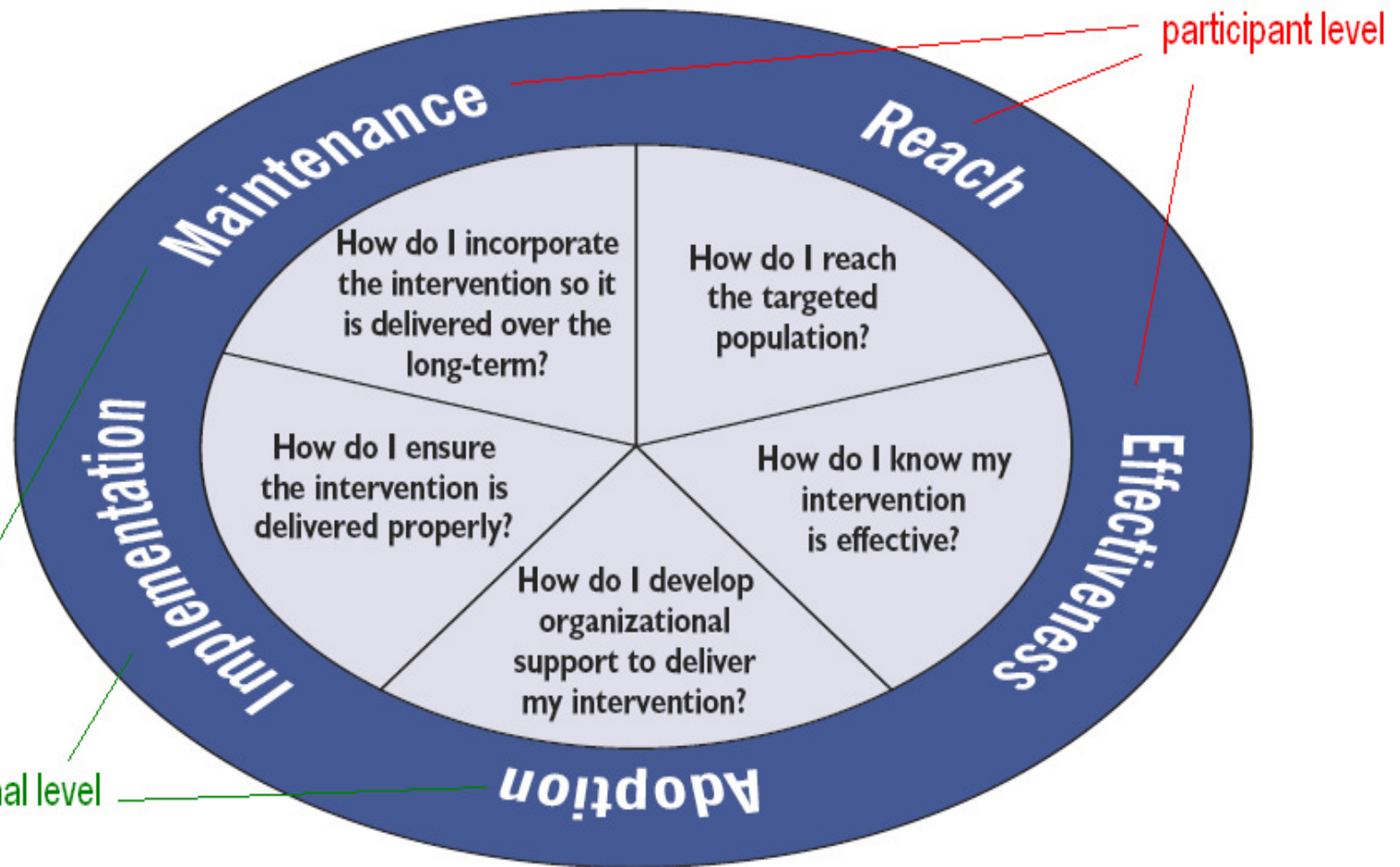
- **“Implementation momentum” → efficacy + advocacy for solution**
- **Evidence for implementation strategy**

(Curran et. al. 2012)

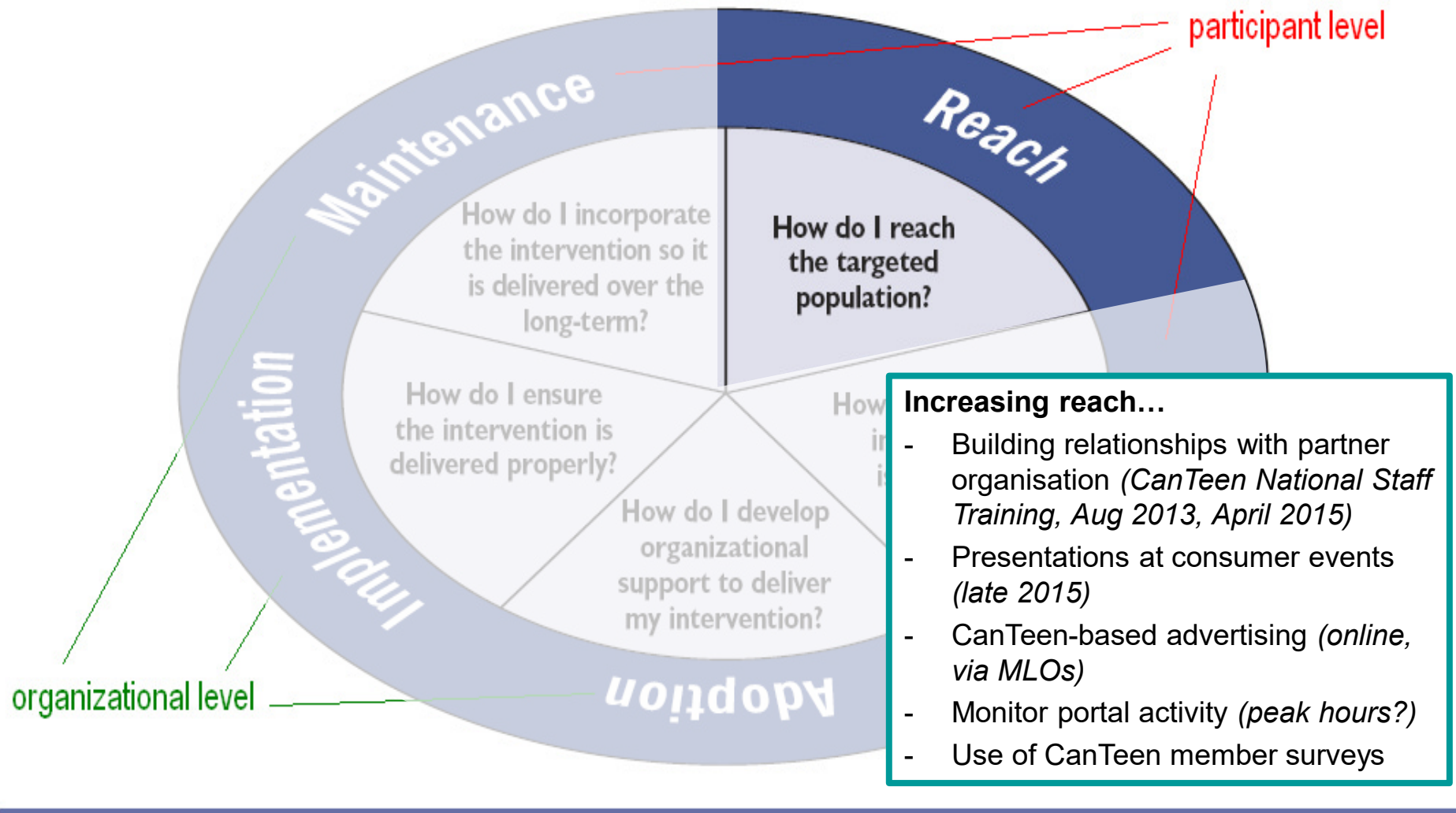
RE-AIM Framework *(Glasgow, Vogt, & Boles, 199)*



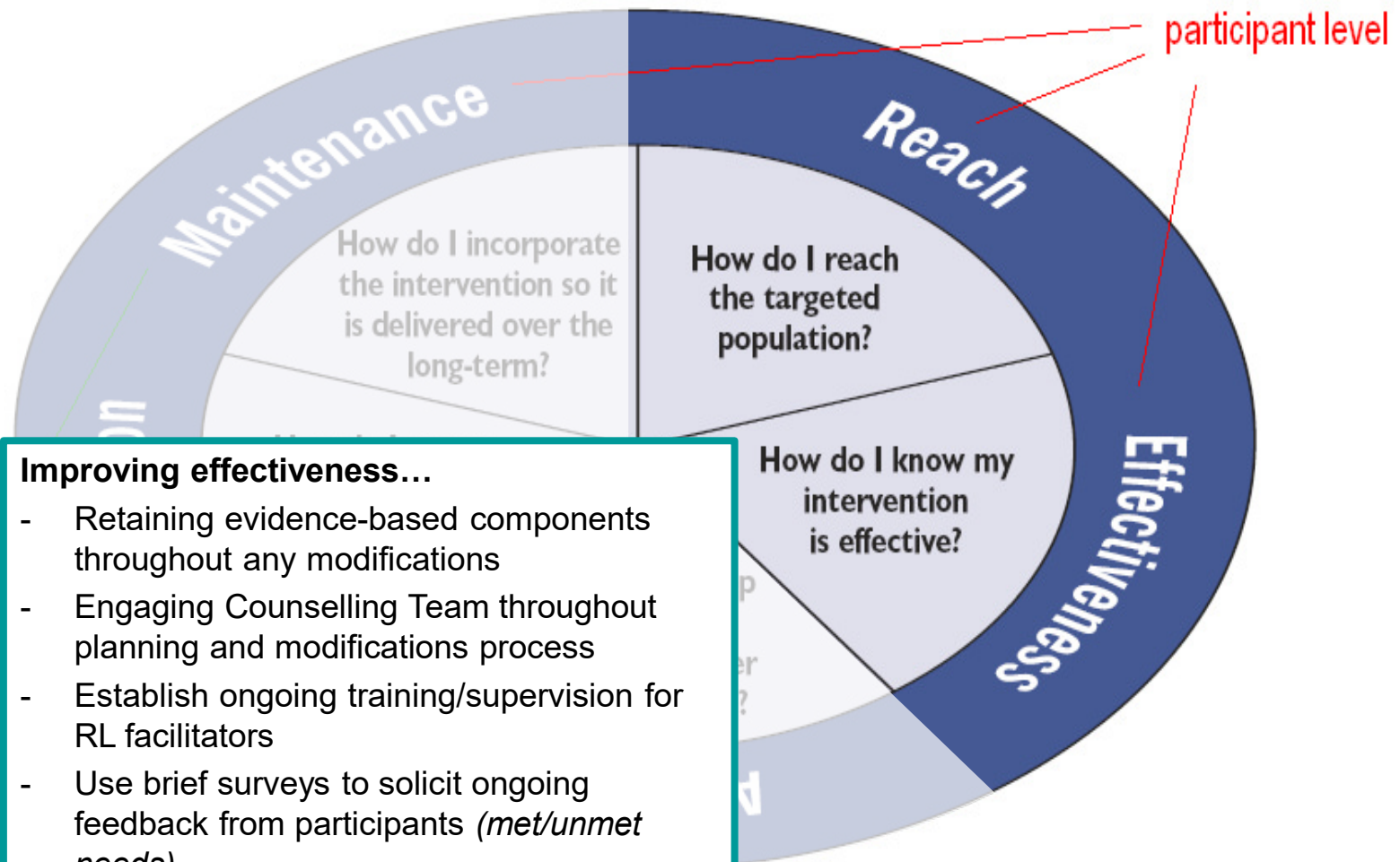
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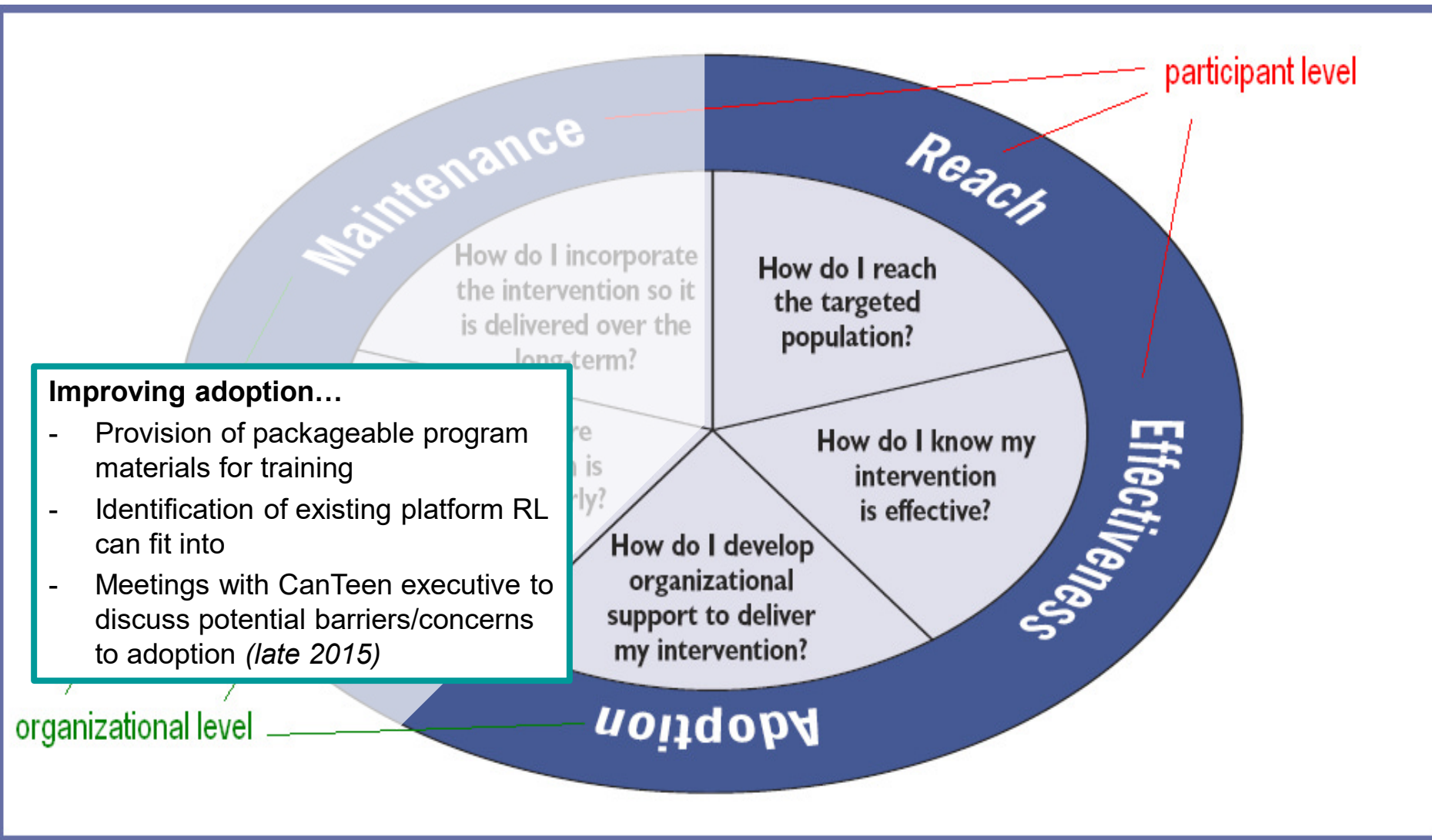
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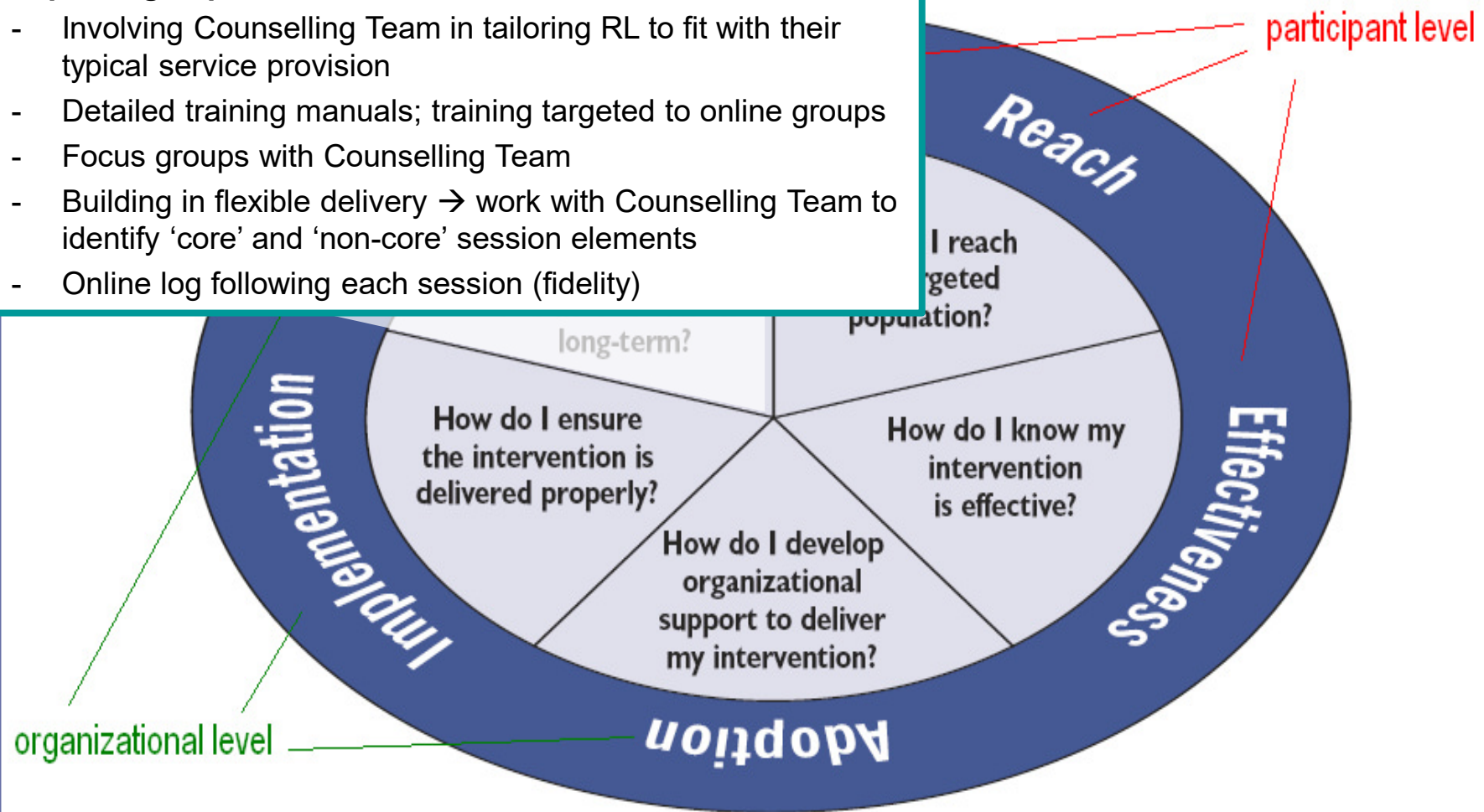
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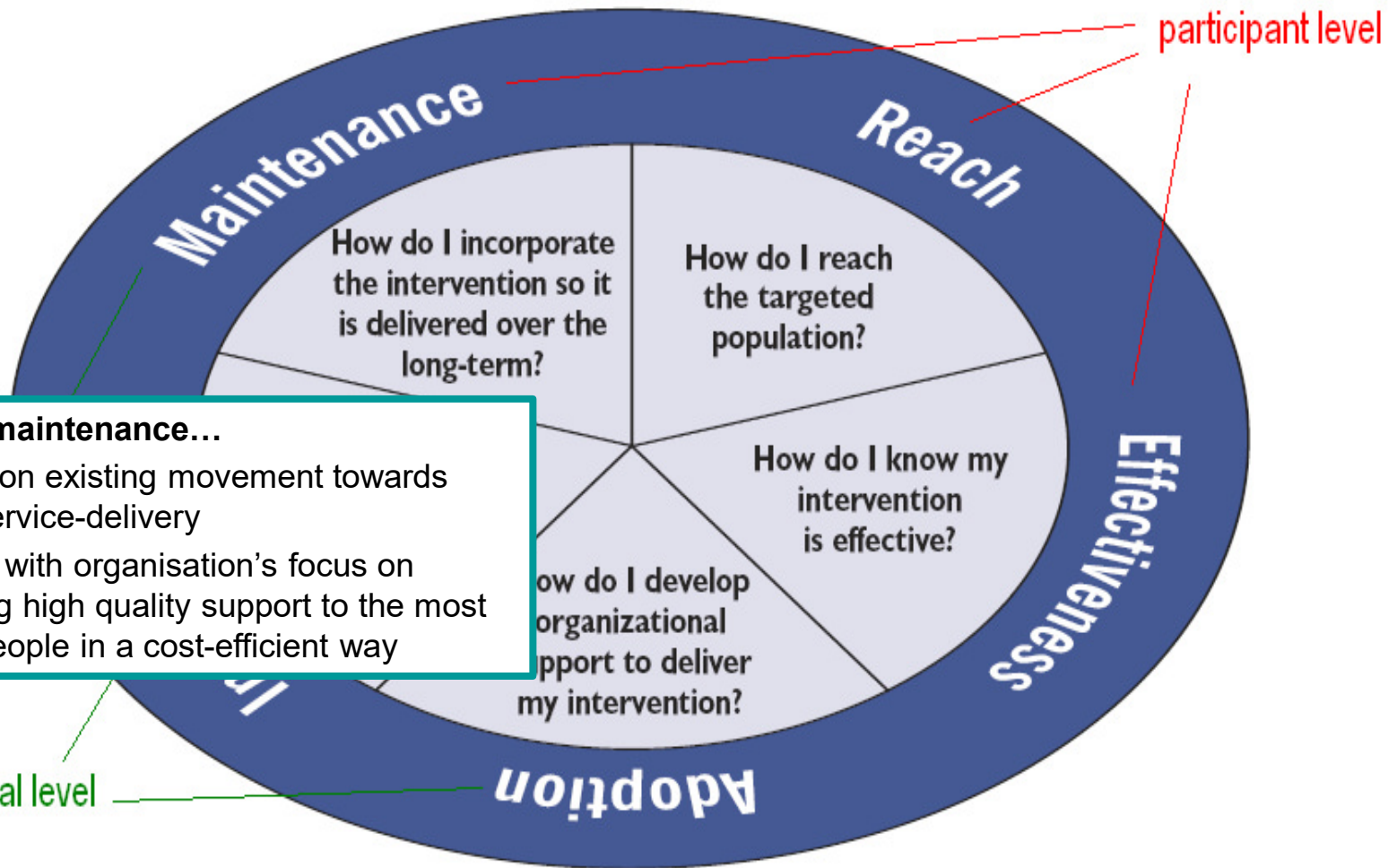
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Improving implementation...

- Involving Counselling Team in tailoring RL to fit with their typical service provision
- Detailed training manuals; training targeted to online groups
- Focus groups with Counselling Team
- Building in flexible delivery → work with Counselling Team to identify 'core' and 'non-core' session elements
- Online log following each session (fidelity)



RE-AIM Framework *(Glasgow, Vogt, & Boles, 199)*



Improving maintenance...

- Building on existing movement towards online-service-delivery
- Align RL with organisation's focus on delivering high quality support to the most young people in a cost-efficient way

organizational level

Implementation planning phase
(0-6 months)

Partner org. staff assessed for eligibility to participate in Recapture Life as a facilitator

Facilitator exclusions:

- Not a registered healthcare professional
- Insufficient CBT experience

Partner staff are trained in Recapture Life content for staff

Partner staff complete training evaluation questionnaire and implementation interview* (Pre-trial). Partner staff report on participant responsiveness, technical issues, reach/organisational uptake, intervention fidelity, financial sustainability, confidence in delivery, and implementation barriers/facilitators.

PARTNER ORGANISATIONS



Partner advertises Recapture Life to service users

Participants opt-in to Recapture Life - partner conducts intake/screening procedures, and allocates participants to groups

AYA exclusions:

- Insufficient English
- On active treatment or in palliative care
- Current substance abuse, acute mental health risks

Intervention phase
(7-24 months)

T0 – Participants complete baseline questionnaire – **UNSW team** sends out questionnaire assessing intensity of treatment⁴⁷, general functioning, psychological distress^{48,49}, perceived peer support⁵⁰, perceived benefit/burden

Participants complete Recapture Life – **partner** delivers 6 week online group intervention, followed by a 6-week booster. **Partner** collects process data.*



MULTIPLE RECAPTURE LIFE GROUPS RUN

UNSW team provides ongoing research and clinical support

Follow-up data collection/analysis
(25-36 months)

T1 – Participants complete post-intervention questionnaire – **UNSW team** sends out questionnaire assessing pre-post changes, in addition to changes to physical health, and ongoing group contact. Participants opt-in to qualitative interview.

Partner staff deliver additional Recapture Life groups to interested participants

Partner staff complete second implementation interview (mid-trial) between delivering groups

Partner staff complete evaluation questionnaire and third implementation interview (post-trial)



Participant measures

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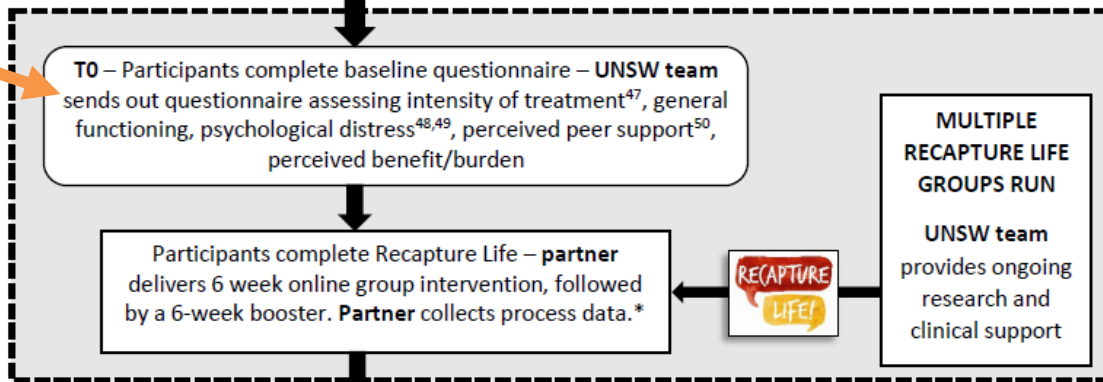
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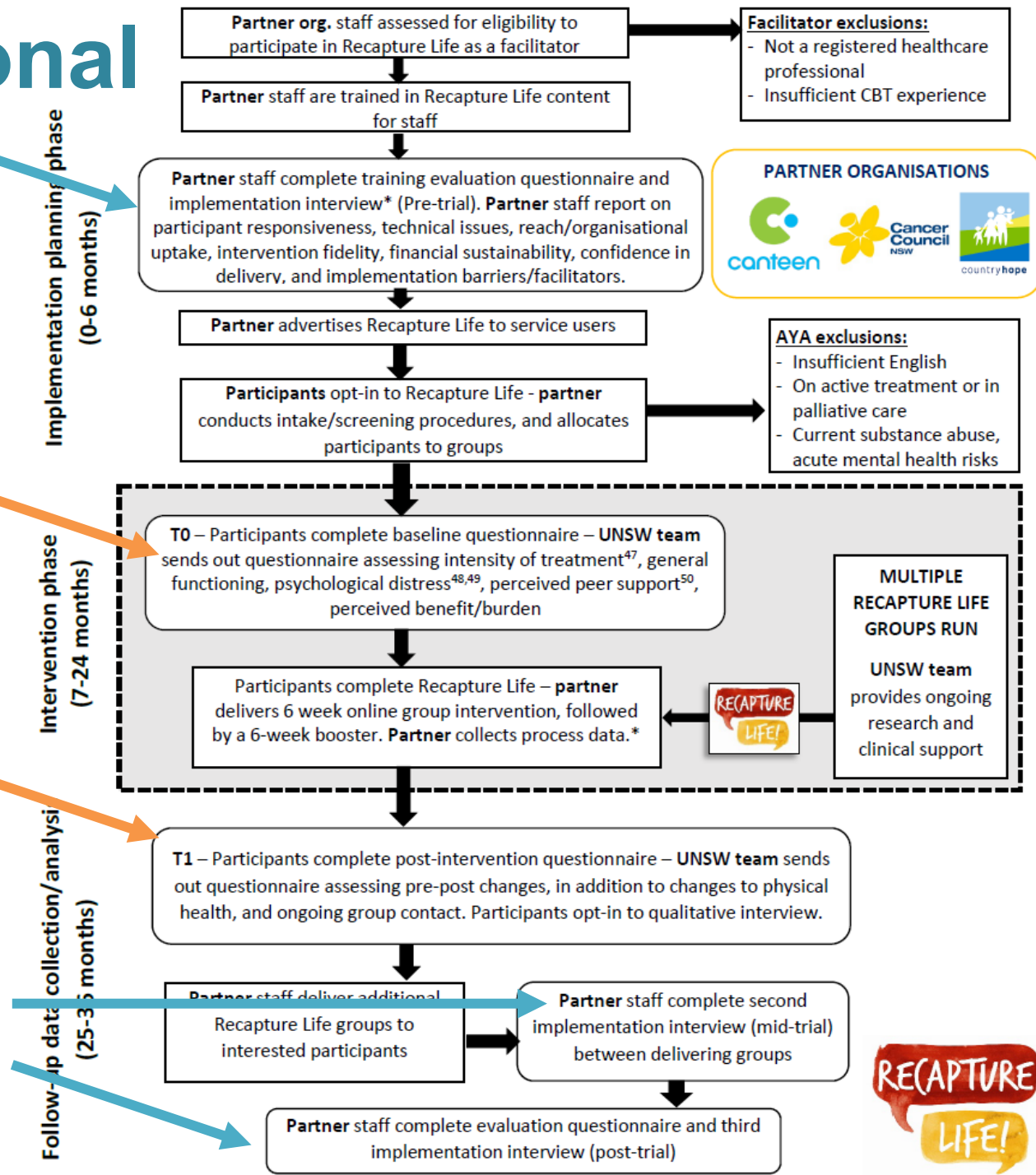


Outcomes: Participant-level

- General functioning (purposely designed items, Q1 + Q2)
- **Psychological distress** (K10 and Distress thermometers; used as both a safety screen and QoL measure, Q1 + Q2)
- **Feelings of peer support** (Cancer Peer Support Scale, Q1 + Q2)
- Benefit/burden (Self-rated items, Q1 + Q2)
- Ongoing group contact (Q2)
- Group sessions – facilitator rating of participation
- Participants' other service use (e.g. additional organisation supports, external counsellors, etc.)

Organisational measures

Participant measures



Outcomes: Implementation

Processes

- **Co-design/adaptation:** Participation, outcomes
- **Training:** frequency, length, modality and content
- **Research collaboration:** Decisions regarding changes to protocol/method
- **Time resources costs:** Personnel time involved in implementing/delivering Recapture Life (including planning, preparation for group sessions, and running group sessions)

Outcomes

- **Adoption/uptake**
 - **Staff:** Total number of staff involved/organisations
 - **AYAs:** Who choose to be involved
 - **Groups:** Total number run
- **Fidelity:** Adapted intervention delivery (content, format)
- **Acceptability** of Recapture Life intervention as a whole from different perspectives (e.g. facilitator, research, management staff)

The
doing bit

Project milestones



Formation of
partnership
with Canteen
Apr 2016

Canteen



The
doing bit

Project milestones

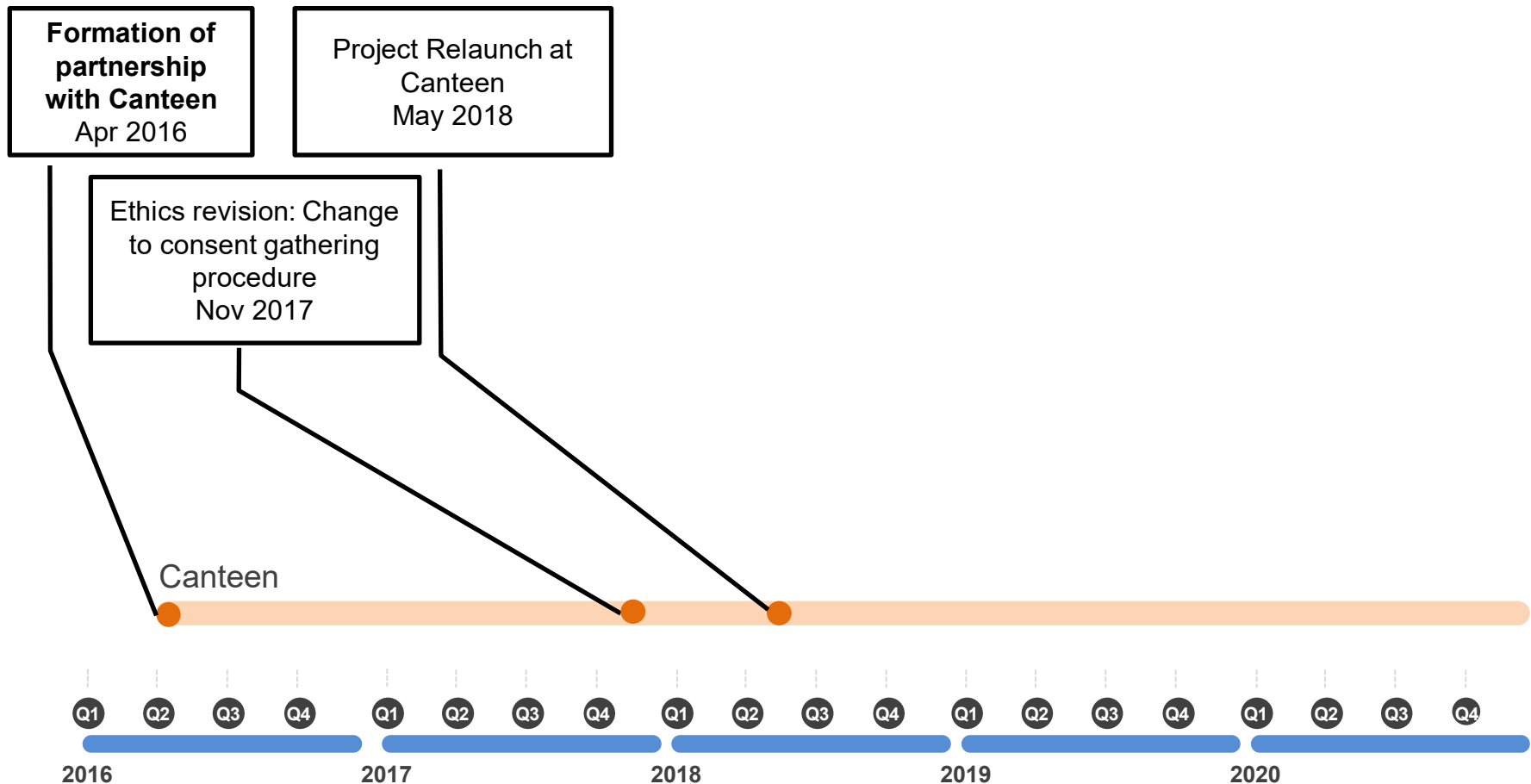


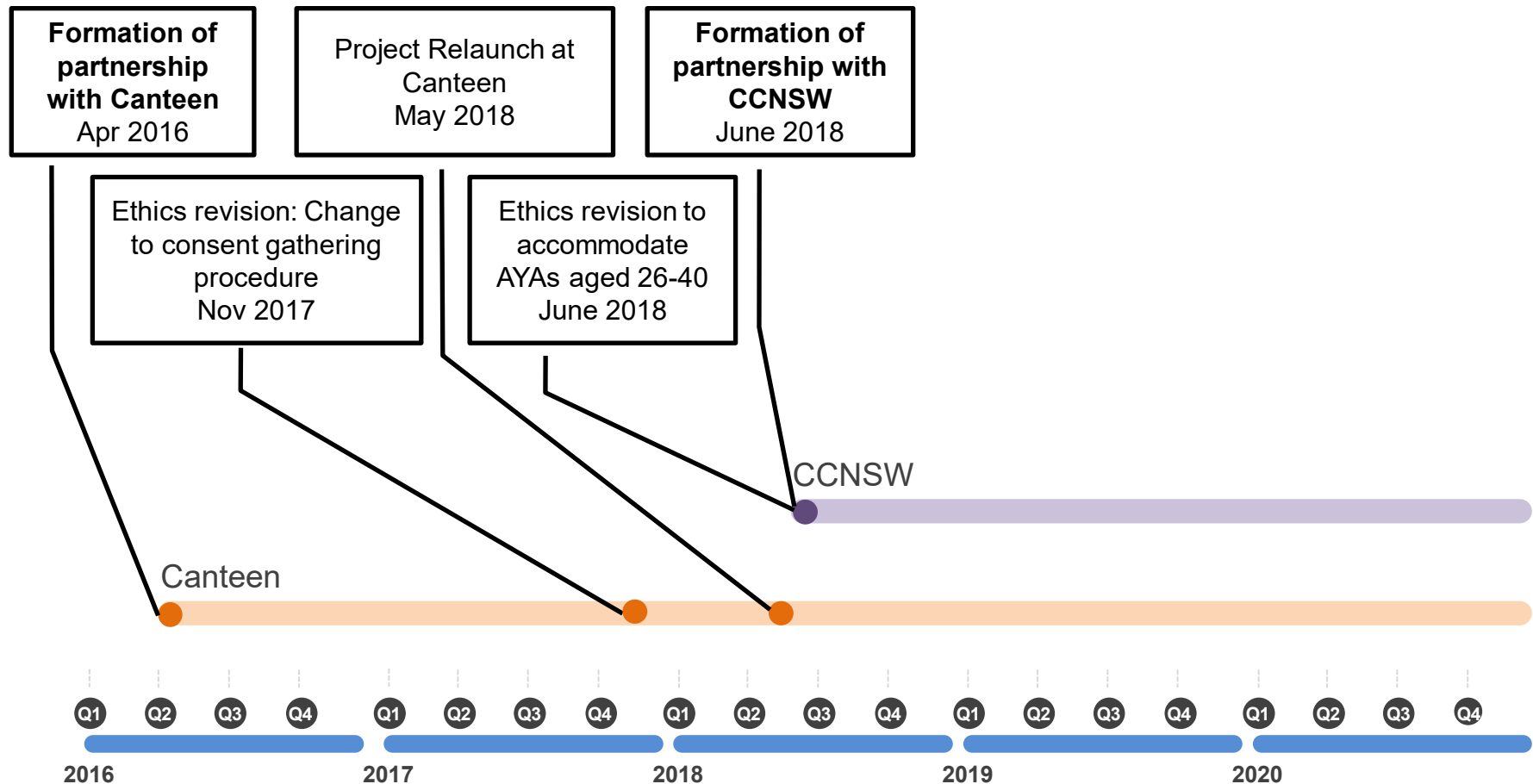
Formation of
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Apr 2016

Ethics revision: Change
to consent gathering
procedure
Nov 2017

Canteen

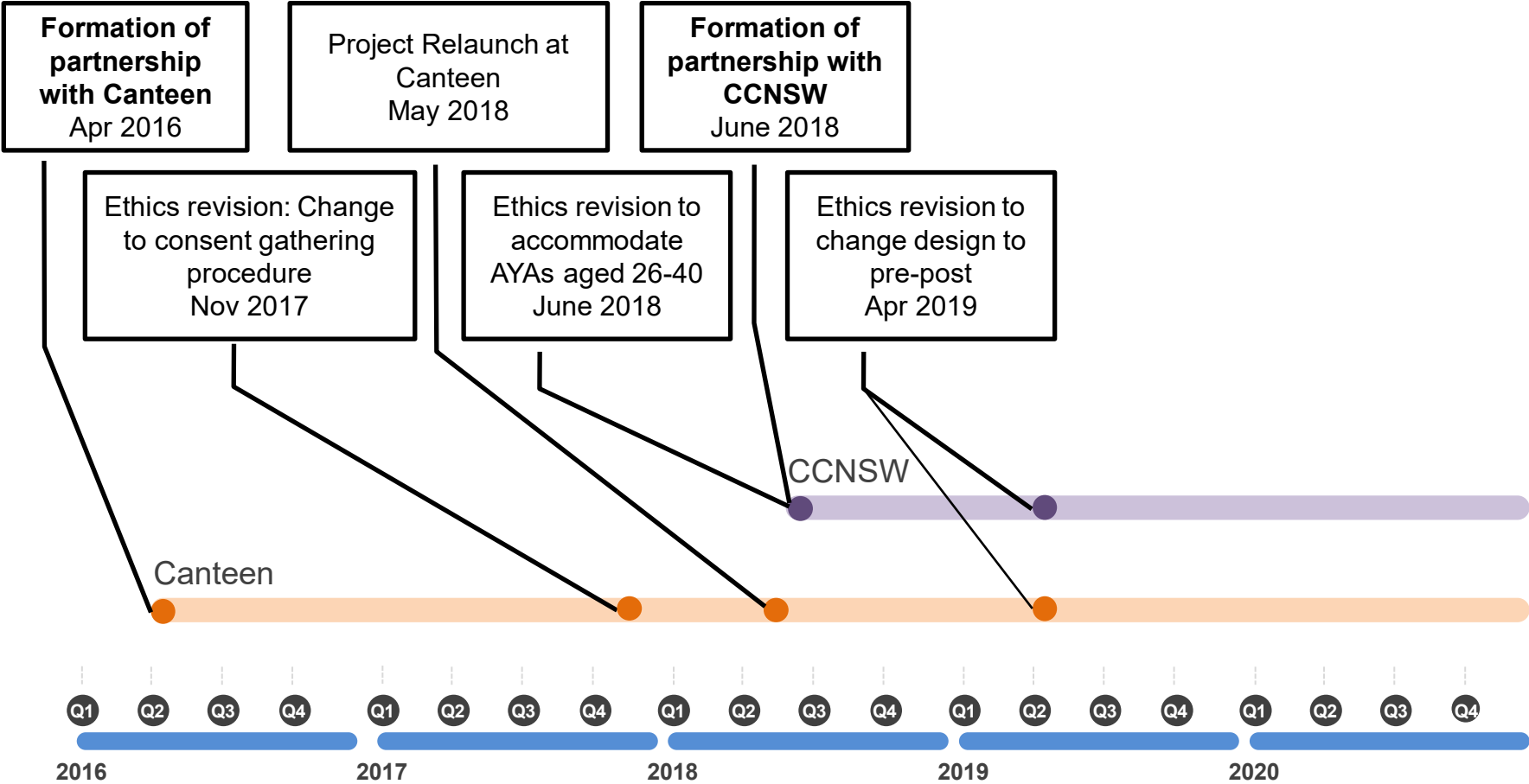


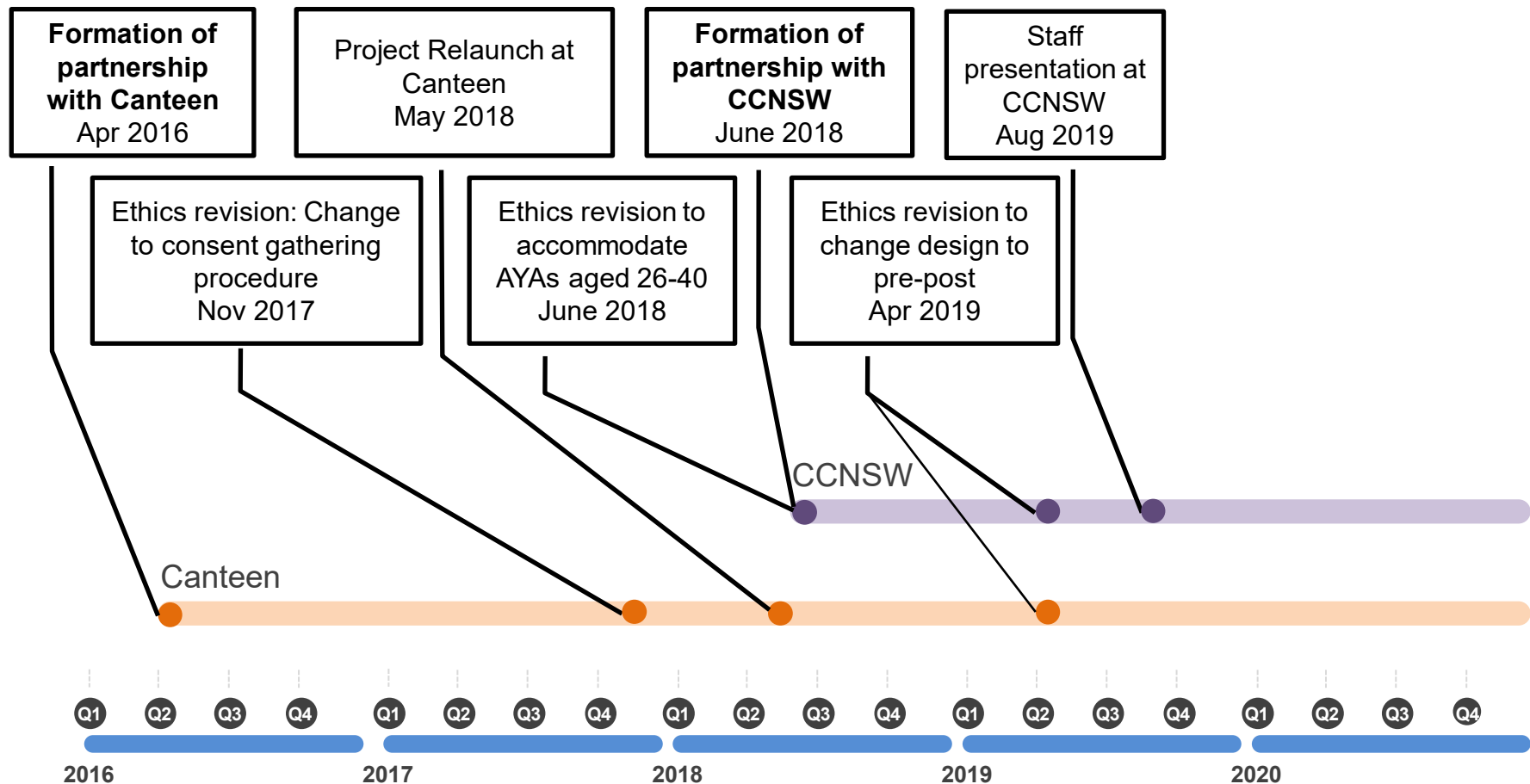


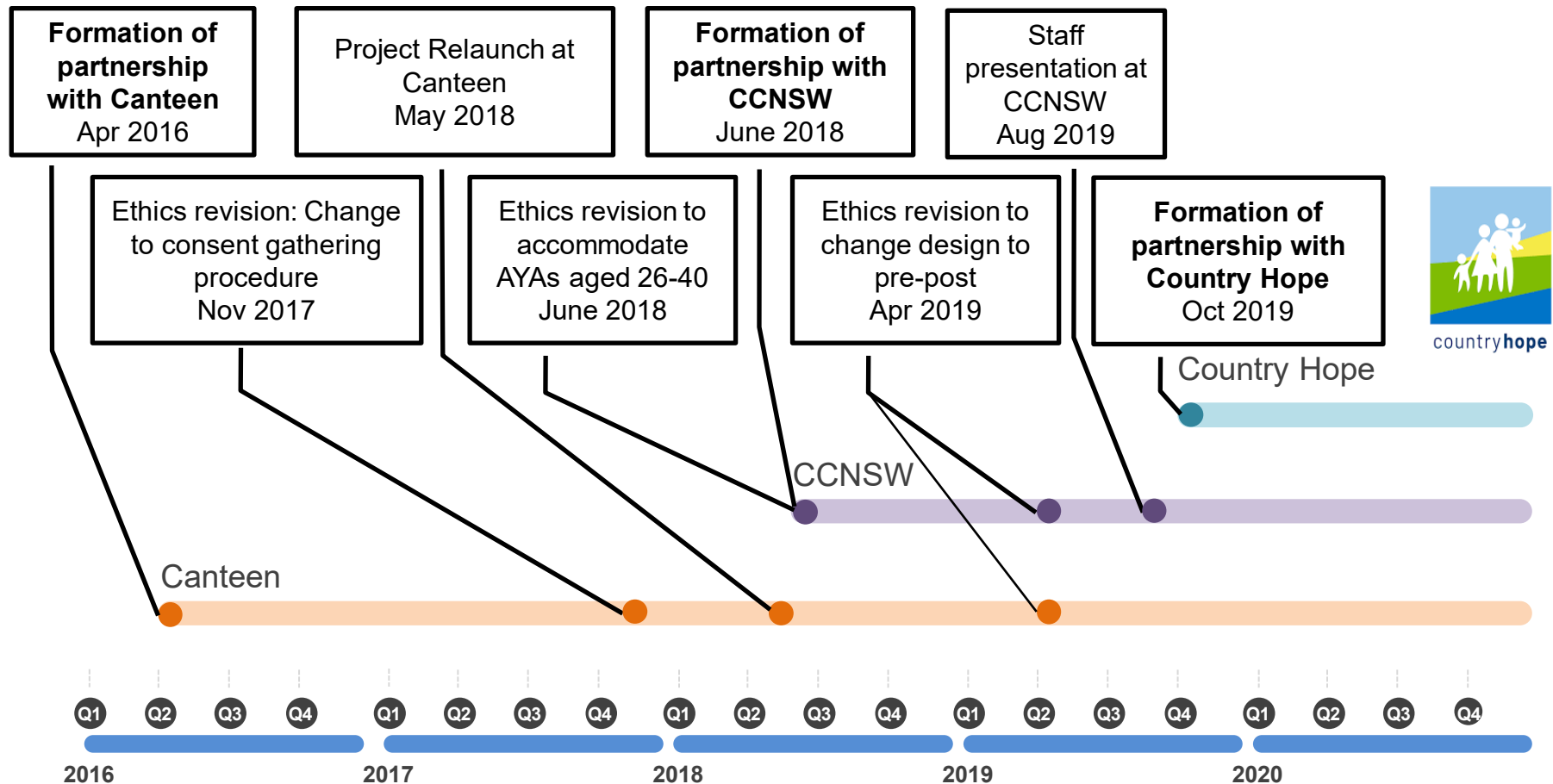


The doing bit

Project milestones

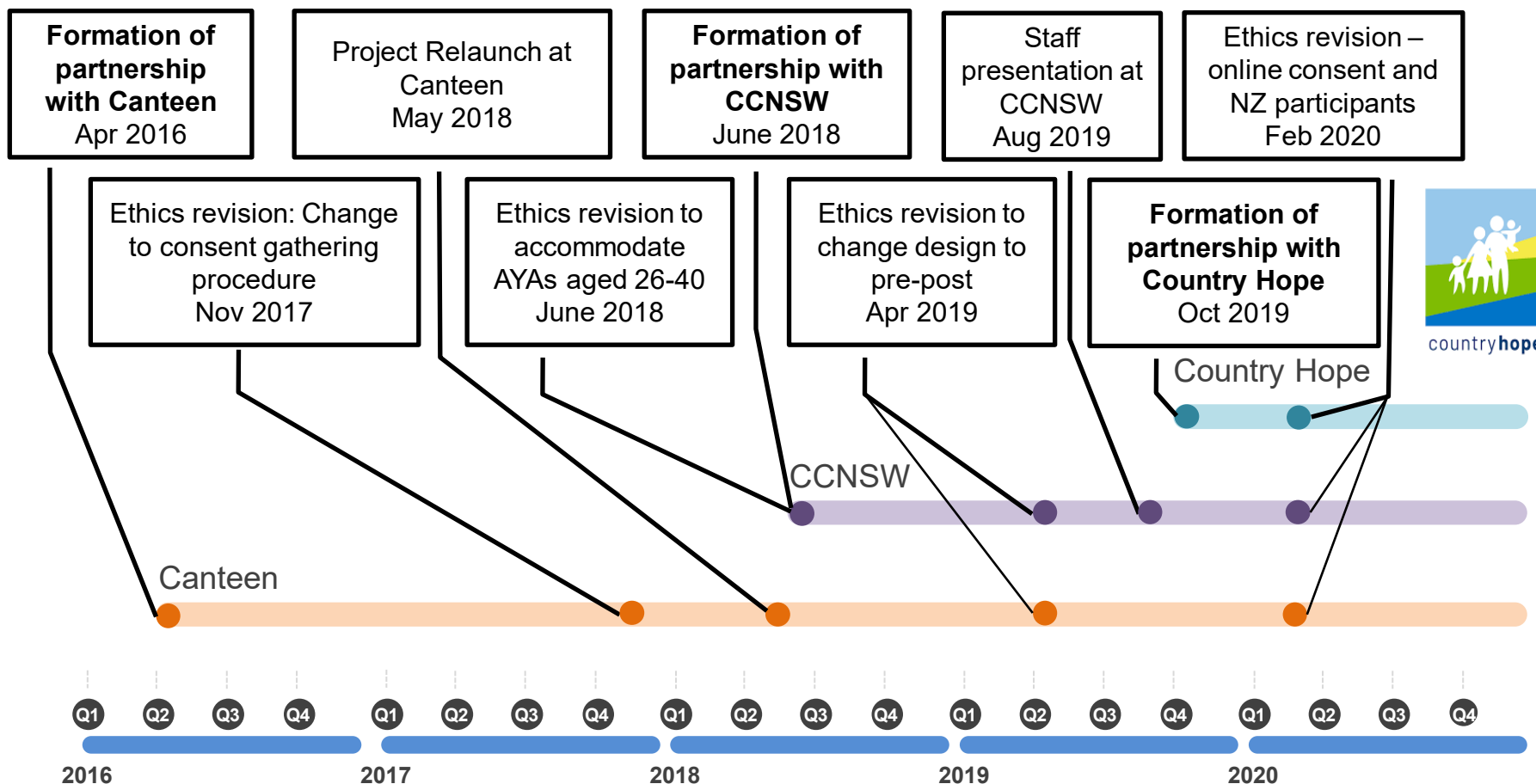






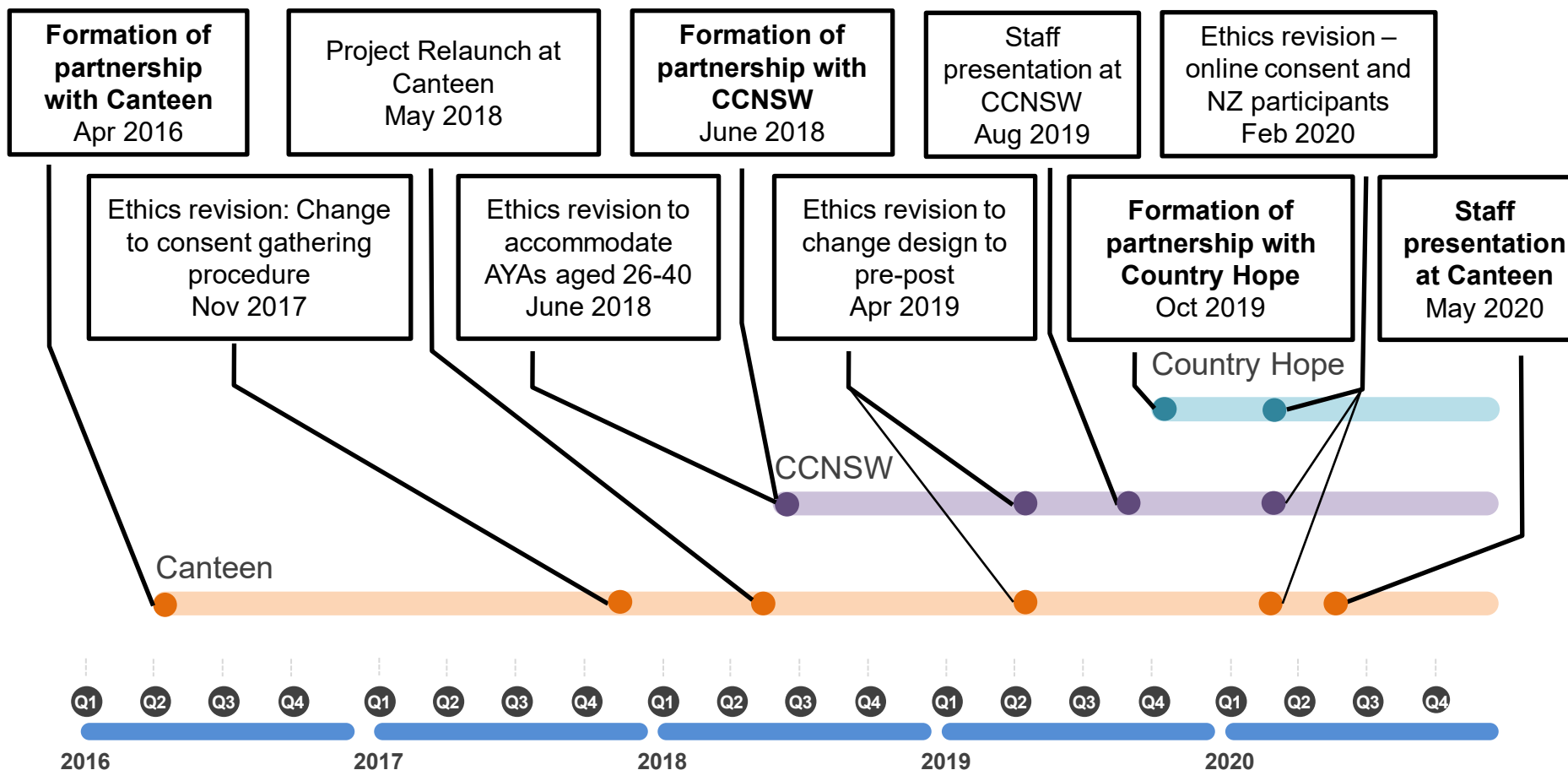
The
doing bit

Project milestones



The
doing bit

Project milestones



The doing bit

Combined progress to date

	Canteen Australia	Cancer Council NSW	The Country Hope Trust	TOTAL
Number of staff training sessions run	6 (1 planning, 6 experiential)	2	1	9
Total AYA Opt-ins	28	6	4	38
Groups run to date	4	1	0	5
Groups pending	1	1	1	3

The community implementation of the “Recapture Life” program

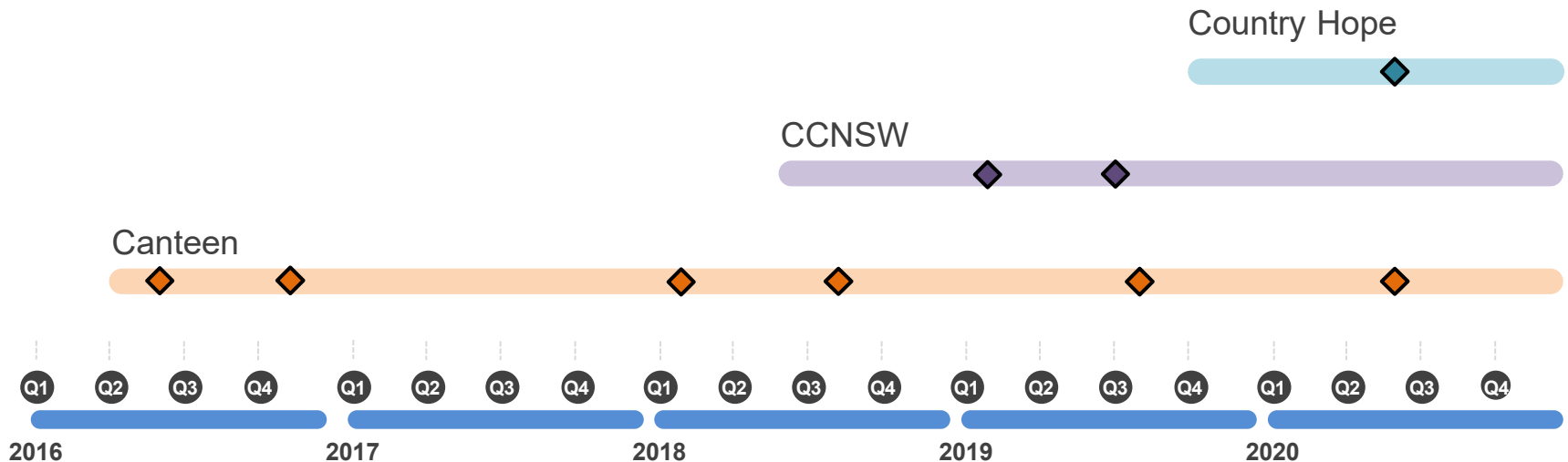
 @usansomdaly



The doing bit

Staff training + groups run

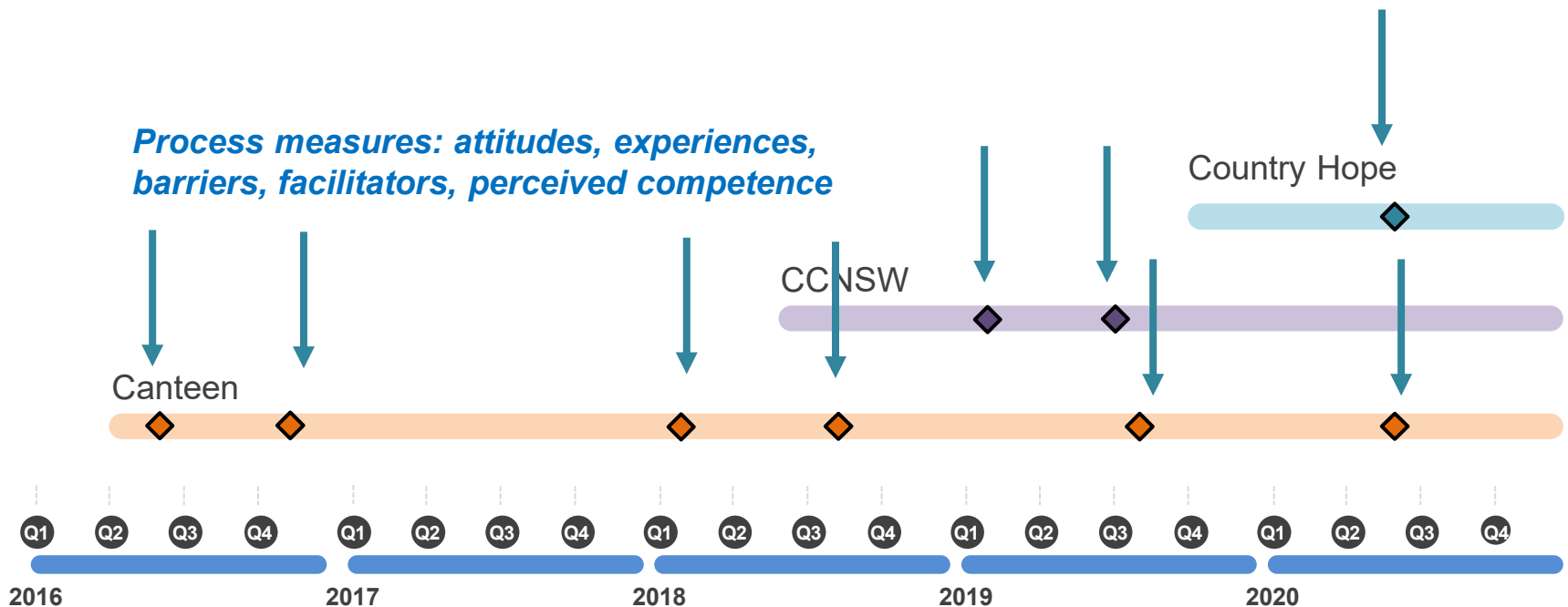
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The doing bit

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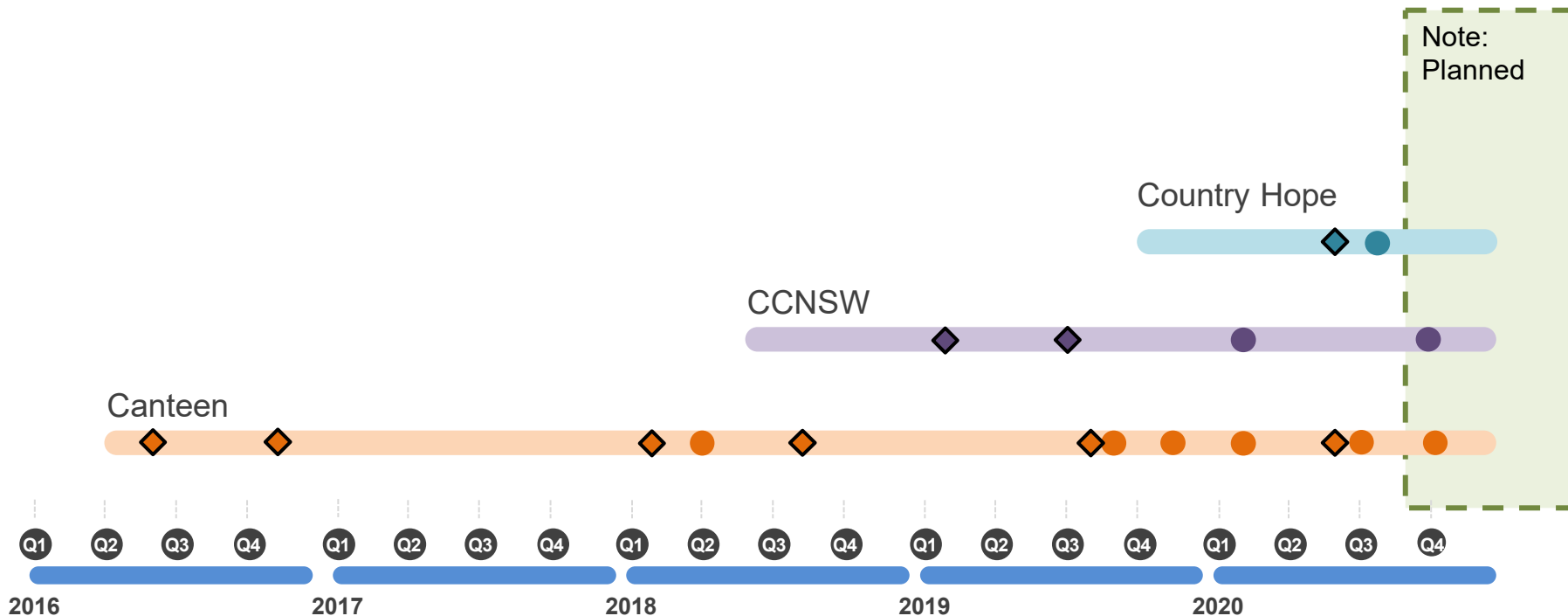
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The doing bit

Staff training + groups run

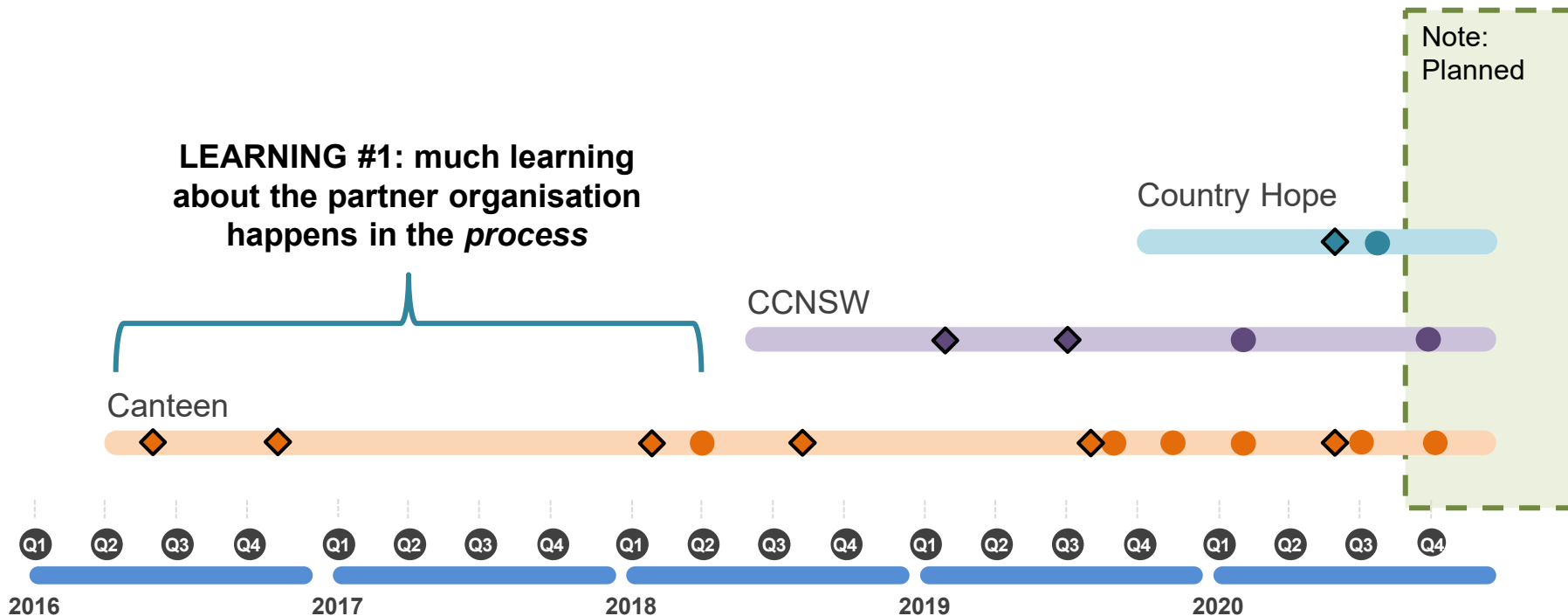
- Multiple staff training sessions run (FTF); done virtually in 2020 (due to COVID-19 pandemic).



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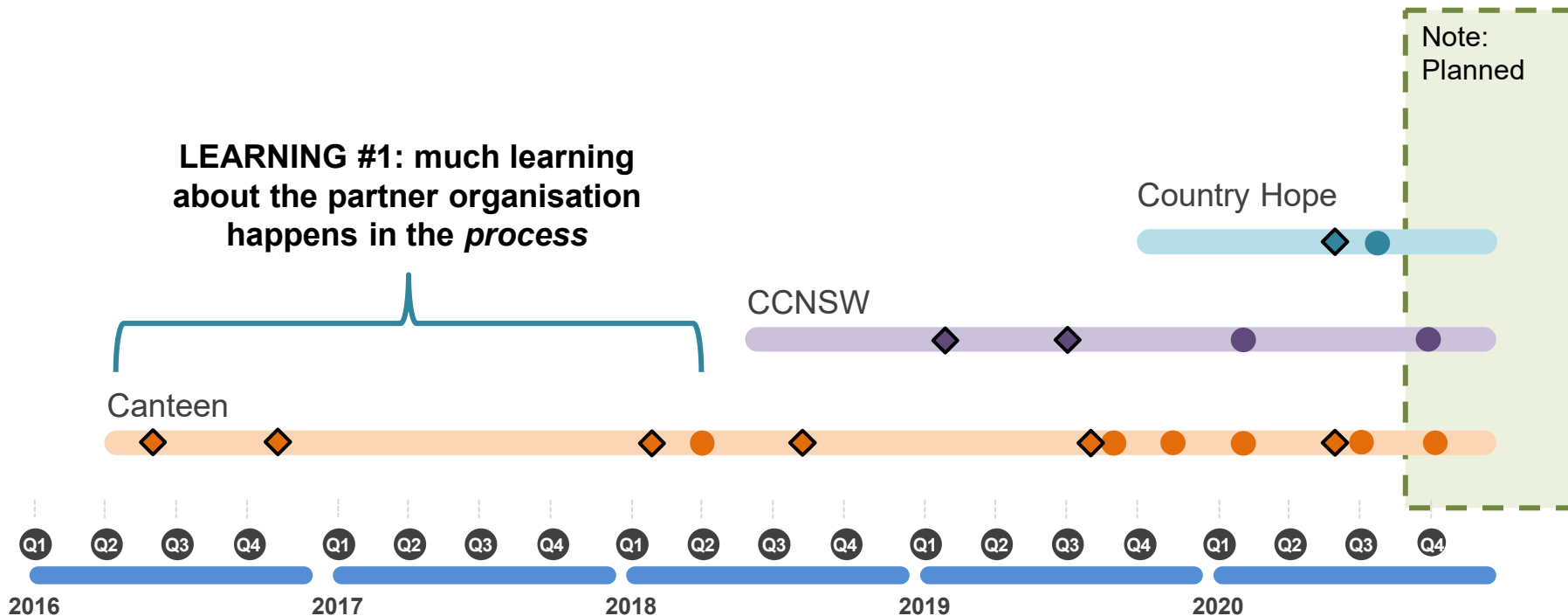
Addressed by:

- Adapting: repeated training sessions held, flexibility
- Responding: Re-convening with project leadership team, 're-launching' study with partner organisation leadership present

The doing bit

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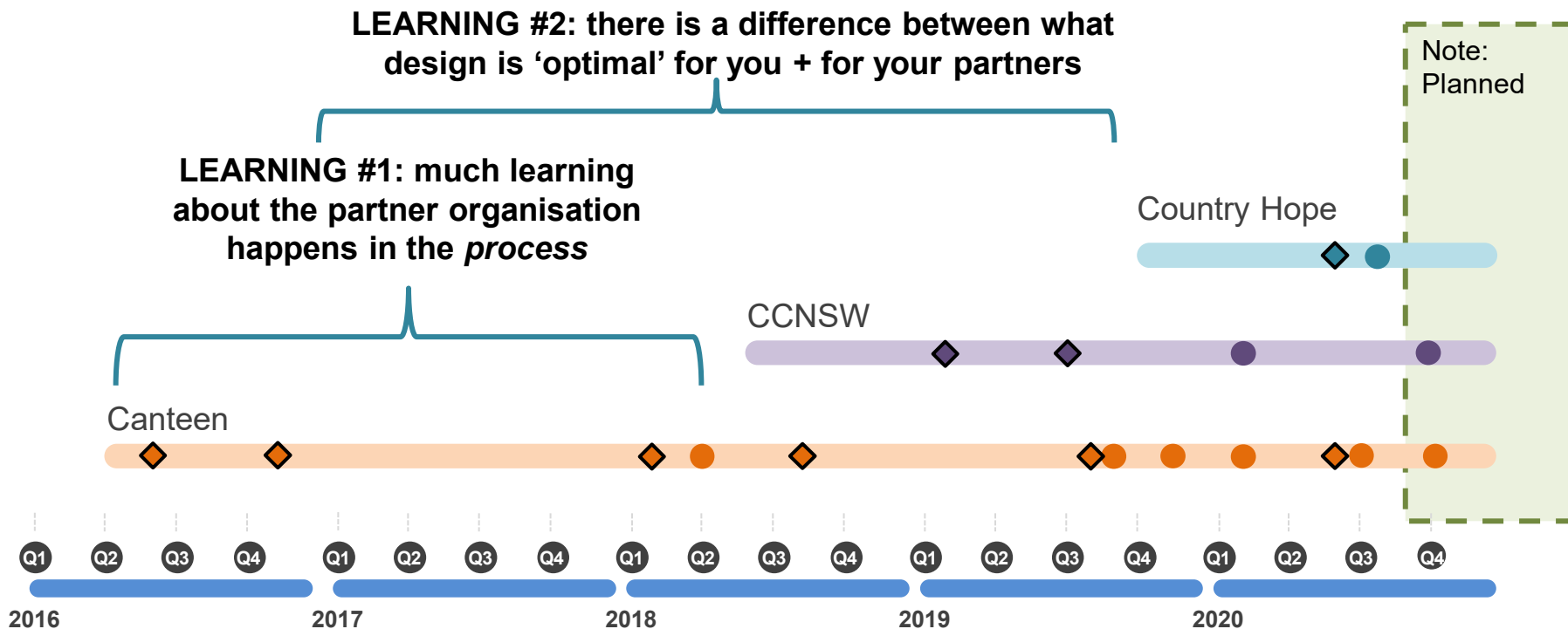
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LEARNING # 2:

Move to pre-post design

- **Original design:** *partially-randomised patient-preference trial*
 - Barriers experienced in implementing
 - Longer time to deliver intervention to AYAs
 - Conflict with community organisations' intent to offer support in an equitable and timely manner
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- **New design:** inclusion of non-randomised control, and still allows for effectiveness assessment + rapid translation that mirrors real-world delivery of a community-based support

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- Slow, iterative process – flexibility needed
- Hybrid II design → likely the right balance for capturing the complexities of implementing the program in the community whilst also capturing participant impact



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Cancer Council NSW Partners

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Australian Government
Cancer Australia



Kids with Cancer Foundation
Australia



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Medical Research Council**

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and **The McPaul family**



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