

# Respectful Practice and Care **Chronic Illness**

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**WELLBEING  
HEALTH &  
YOUTH** NHMRC Centre of  
Research Excellence  
in Adolescent Health

**YR** **YOUNG &  
RESILIENT  
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CENTRE**

## Why it matters?

10 - 20% of adolescents have a chronic physical illness, and over 90% of them will live into adulthood. 47% of Australian adults (over 18 years) have one or more chronic conditions (Australian Institute of Health & Wellbeing, 2022).

## Definitions

Chronic diseases are long lasting conditions with persistent effects. Their social and economic consequences can impact on peoples' quality of life. Chronic conditions are becoming increasingly common and are a priority for action in the health sector.

The National Strategic Framework for Chronic Conditions uses the term chronic conditions to describe a broad range of health conditions, including: chronic and complex health conditions mental illness trauma disability genetic disorders.

Chronic conditions: have complex and multiple causes, may occur as a single condition in a person, or along with other diseases (comorbidity), usually progress gradually, can occur at any age, can affect quality of life, and can create limitations and disability.

## Working with young people and researchers with lived experience of chronic illness, from the inception of your research to the dissemination of findings

### Prepare

#### What to consider before you engage

- Have you had an experience of chronic health (yourself, friends or family)? What happened? What do you wish you had known about this experience beforehand?
- What are some of the assumptions you or others might make about people with invisible disabilities?
- Have you reviewed the existing guides and research on how to work with young people living with chronic illness?
- Have you reached out to seek advice from other organisations who specialise in engaging with young people with chronic illness, to consider how to best prepare to engage with this cohort?
- Is there an opportunity to collaborate/partner with an existing organisation who engages young people in this cohort on your research project?
- Have you considered how you make accessible pathways for young people with chronic illness to find and get involved in your research? This could include considering how recruitment processes are flexible for varying needs such as time (flexible time options), location (online/offline and accessibility of venues or digital platforms), and whether/how support people/carers need to be involved.
- The community is not set up for people with chronic illness to be social or independent. How can we help them to feel more comfortable and consider the everyday challenges for them?



## Connect

### What to consider when you engage

- Who shares perspectives and who doesn't? How do you know what you think you know? Who told you? Who has not been consulted?
- Have you asked young people (and any other people involved) what they need to participate? Have you removed physical, transportation, information and communication barriers or provided reasonable alternatives?
- Have you addressed attitudinal, environmental and institutional barriers to young people's engagement?
- What does privilege look like in this context? Are there differences across generations? What does discrimination look like in this context, and across generations?
- When you initially connect with young people with chronic illness, consider how you might create a space for young people to be seen for themselves first, instead of attached to their illness.
- Have you checked in 1:1 individually with the young people involved in your research to understand:
  - How they want to be viewed through the engagement process – noting that whilst chronic illness/medical condition may have a significant impact on their lives, it may not be the primary way they identify or want to be known. People with chronic illness and disabilities tend to have preferential terminology, and it is important to ask each individual what their unique preferences are.
  - Their unique preferences around engagement and any support they require to enable their full participation in your research project. Even if you are conducting research on a specific medical condition, each young person's experience of this could vary immensely. Consider how you can be sensitive and aware of the different types of chronic illnesses, two people with the same diagnosis can live very different lives, so never assume their abilities or limitations.
- Remember: it is your responsibility to make the necessary adjustments to create an enabling environment for all young people to engage in and to do this in a way which listens closely to the specific young people you are working with. You also need to have realistic expectations when it comes to connecting with young people with chronic illnesses. Things for these young people can change day to day, minute to minute, so it is always good to be realistic and flexible. If things don't go to plan or schedule. It's also important to always address the young person directly.
- Have you considered how associated risks with COVID-19 may impact young people with chronic illness/disability? Have you asked young people what they need and feel comfortable with? Have you put appropriate COVID-19 safe planning in place, and communicated this with all people engaging in activities together?

## Reflect

### What to consider after you have engaged

- What assumptions am I making about young people's abilities, how they prefer to be known/identify their unique experience of living with chronic illness?
- How am I viewing myself and young people in this process?



## Key points of consideration

- Researchers must empower young people to partner with them so their lived experiences can inform, educate and improve research outcomes that matter to young people with chronic illness.
- Consider the differing adjustments and unique considerations for the individual young people you are working with, asking and not assuming about their preferences.
- Be mindful that there are visible and invisible chronic illnesses and disabilities.
- Balance not being afraid to ask questions but also 'reading the room' and identifying when to stop asking questions.
- Acknowledge and consider the role of intersectionality in young people's lives. All health services and researchers must be inclusive and provide safe spaces for young people with chronic illness. Be mindful of trauma/stressors related to previous interactions with the healthcare system which young people with chronic illness may have experienced. Listen and think about how things may affect their quality of life. Think before you assume! Validate their feelings and symptoms
- Consider if and how to involve or accommodate for carers/support workers in the case of some young people with chronic illness. You may have to navigate the balance of young people's individual rights to privacy around their health and healthcare, with practical needs for support. Take into consideration their preferences to better support, i.e choice to have or not have a support person present.

## Resources

- [Women with Disability Australia \(WWDA\)](#)
- [People with Disability Australia – Language Guide](#)
- [Agency for Clinical Innovation – Transition Care Network](#)

## Further reading

[Australian Institute for Health and Wellbeing – Young Australians](#)

## References:

[Fact Sheet: Chronic Illness, Sydney Children's Hospital Network](#)

[Chronic Conditions, Australian Institute of Health & Wellbeing](#)

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