



Connecting with neurodivergent young people through user-centred design

A practical guide to designing innovation in partnership with neurodivergent children and young people

SUMMER 2026

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Implementing user-centred design with neurodivergent children and young people

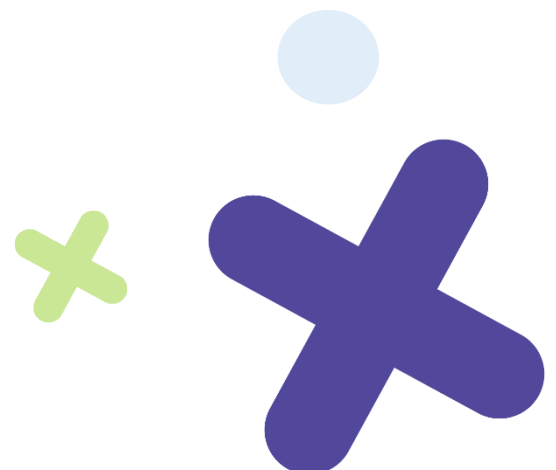
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Introduction

This guide supports teams to design products, services and systems through user-centred innovation. It centres neurodivergent children and young people (ND CYP) as active shapers of ideas, delivery and evaluation, rather than involving them only at the point of feedback. The guide is designed to help innovation better reflect real-world needs and improve impact of digital solutions.

Grounding and developing innovation in lived experience, especially for neurodivergent young people, benefits both the organisation developing the product or service and users:

- Lived experience reveals needs that desk research alone cannot capture
- Inclusion reduces the risk of harm, exclusion and unintended bias, building trust and accessibility
- Involvement improves efficiency and reduces costly redesign
- Diverse voices strengthen equity and relevance.

Purpose of this guide

The purpose of co-developing this guide is to strengthen how **neurodivergent children and young people (ND CYP)** are meaningfully involved in the design and evaluation of innovation. We sought to hear how young people want to be involved, what support they need to participate safely and confidently, and how lived experience can be centred and valued throughout design and implementation. In parallel, we explored how innovators are currently involving ND CYP, identifying examples of good practice alongside common gaps and challenges.

The guide was developed combining a literature review, collaboration with innovators and engagement with ND CYP through a workshop with young partners from Surrey County Council. This work builds on an earlier guide co-designed with YMCA Downslink e-Wellbeing Ambassadors and was funded by the Office for Life Sciences and led by Health Innovation Kent Surrey Sussex.

These insights were used to co-produce a practical and accessible framework presented in this guide, including clear principles, and a concise checklist to help innovators plan meaningful, inclusive user-led approaches. Innovators are encouraged to engage with Health Innovation Kent Surrey Sussex's **Working with People & Communities Innovator Support Offer** to embed inclusive involvement, community insight and meaningful partnership throughout the design and delivery of innovation.



How to use this guide

This guide is designed to be practical and flexible, supporting you to develop understanding, confidence and skills for inclusive and effective user-centred design with neurodivergent children and young people (ND CYP) in your organisation.

You can use the guide to reflect on current practice, identify gaps in how ND CYP are involved, and strengthen the quality and impact of engagement.

The core concepts in user-centred design, insights from youth voices, examples from innovators and checklist can help you plan opportunities for user-centred design, identify resources needed, and decide what type of involvement is appropriate to enable safe, accessible participation.

The guide offers prompts, examples and points of reflection to help you design involvement that is proportionate, transparent and meaningful.



Key concepts for listening to user voice

What is user-centred design?

User-centred design is not simply about involving people in design activities. It is an approach where the needs, experiences, preferences and contexts of users are the primary drivers of what is designed, how it is designed, and whether it is considered successful.

This means:

For neurodivergent children and young people (ND CYP), this requires designing **with and around their ways of thinking, communicating and experiencing** the world, rather than expecting them to adapt to systems that were not designed with them in mind. Undertaking user-centred design with neurodivergent children and young people is important in creating inclusive, impactful innovations, particularly in mental health support and service design.

- Design begins with understanding real lived experience, not assumptions
- Decisions are guided by user insight at every stage
- Solutions are iteratively shaped, tested and refined based on user experience
- Success is defined by whether the innovation works for the people it is intended to support



Distinction between user-centred design and patient & public involvement (PPIE)



User-centred design focuses on ideating, developing and scaling products or services that **meet the needs of those intending to use them**. This can look like engaging with users to understand how the product functions and delivers for them, helping to improve usability, accessibility and experience. Users might be involved in helping to discover and develop the product through co-design, **help test and refine** through evaluation, or help scaling of emerging products through prototyping. User-centred design places the end user at the heart of the process in order to design products that provide benefit to the user, improving access to products, efficiency and fewer iterations for innovators.

Patient and public involvement (and engagement) (PPIE) is another way of involving people with lived experience through **learning what is relevant to them**. PPIE is often focused on making a project relevant, such as a piece of research or new service, involving the public in shaping the project topic, direction and delivery. This acknowledges that **patients, carers and families are experts in their own right** and that they belong in partnership with those of learned experience, such as clinicians, service designers and academics. PPIE aims to enable accessible, inclusive research with shared decision making. Whilst PPIE can involve co-designing outputs, such as research questions, promotional materials and surveys, PPIE involvement usually exists on a smaller scale than user-centred design and user testing. People with lived experience might get involved in being a regular advisory group for a research topic, rather than evaluating a particular product.

Innovating for neurodivergent CYP could involve elements of both user-centred design and PPIE concepts and methodologies, and it is important to consider for what purpose you are centring people with lived experience and their ideas. Both emphasise the importance of involving neurodivergent CYP when designing and implementing processes, with UCD focusing on the user experience and PPIE contributing to improved relevance and priority-setting.

In practice this might look like:

- User-centred design: testing whether a digital tool is accessible, engaging and usable
- PPIE: involving CYP in deciding what the tool should do and why
- Combining both approaches to ensure innovations are usable, needed, and equitable

Innovator case study - Brain in Hand



How does Brain in Hand support ND CYP?

Brain in hand is a neurodiversity support platform combining specialist human coaching, always-available digital tools, and 24/7 on-demand human support.

How does Brain in Hand approach user-centred design?

User-centred design is embedded across the organisation, with dedicated roles supporting co-production and the development of internal guidance for involving lived experience. Recently, in an 8-week co-design project, neurodivergent young people worked with the team to redesign mental health and wellbeing outcome measures after existing tools were found to be inaccessible and not always meaningful. The learning from this experience has been shared in an online report "[Co-designing a Managing & Coping Metric with Autistic and ADHD Users.](#)"

Find out more

<https://braininhand.co.uk/>

Important terms

When planning to involve people with lived experience in consultation, design or testing processes, complication can occur due to the language that describes involvement, especially where both user-centred design and PPIE are helpful. Below is commonly used terminology, acknowledging that involvement exists in different forms and across different disciplines.

Co-design

People with lived experience collaborate to create a product throughout the conception to delivery pipeline, specifically having a key role in creating the project outputs.

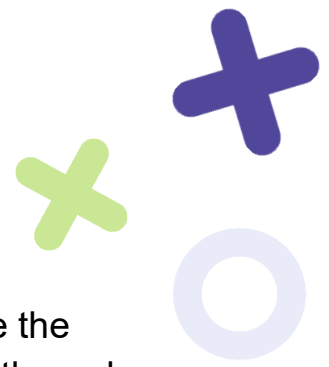
Co-creation

Collaborative, creative problem-solving through engagement with lived experience stakeholders. Involvement is inbuilt throughout the design process.

Co-production

An engagement approach where stakeholders help to creatively produce a previously agreed project output, defined solution or strategy, within a particular scope.

Design thinking



Design thinking is a **structured, user-centred approach** to innovation that supports teams to understand real needs, define the right problem, **generate ideas, test solutions** and refine them through iteration.

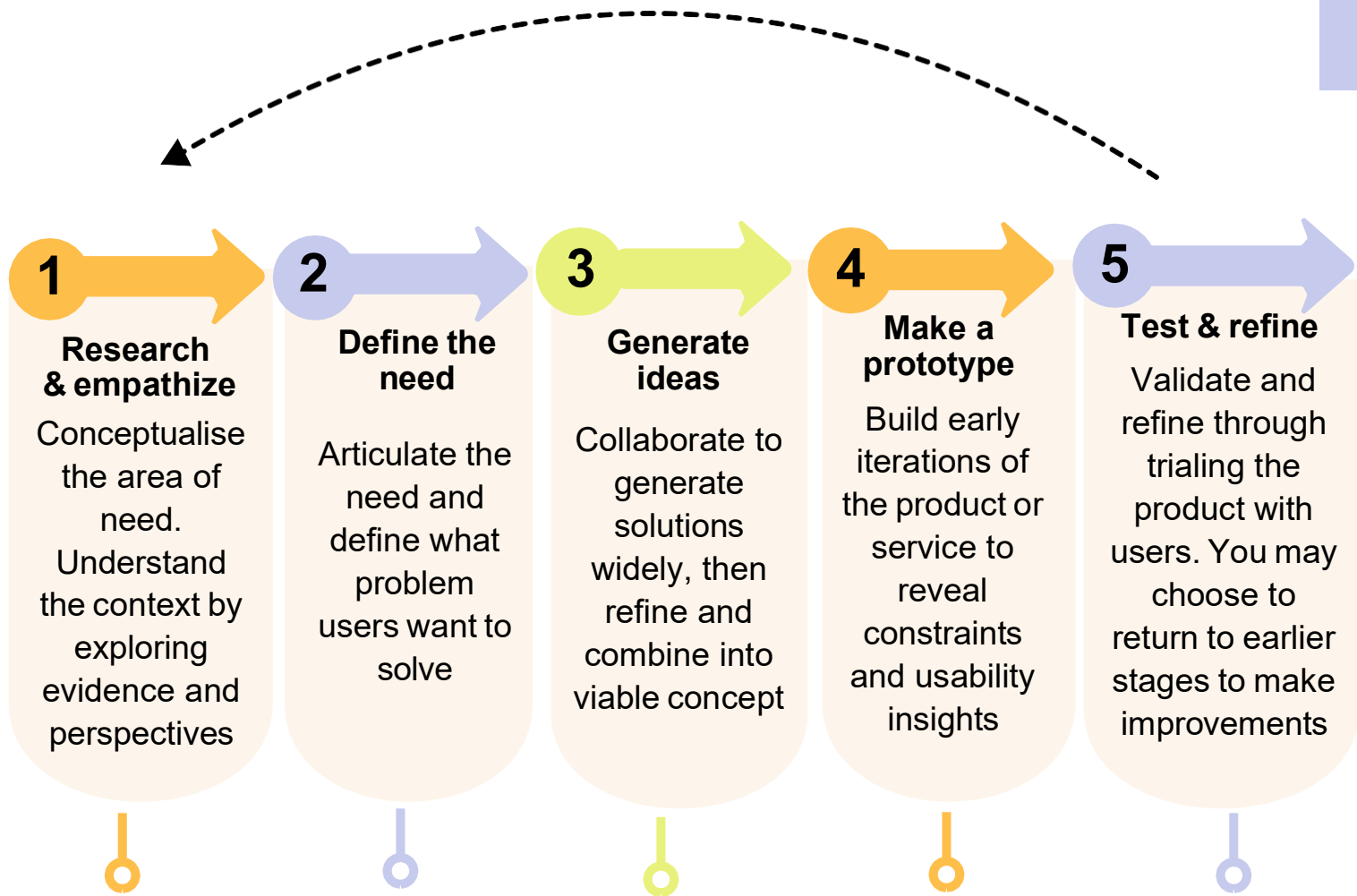
- Takes a solution-based approach to design, with innovators thinking how a product solves a particular real-world challenge
- Ensures innovations are desirable, usable and effective for the people they are intended to support
- Does not need to disrupt existing innovation processes but adds key, real-time insight to inform decision-making
- Reduces the risk of making inaccessible and ill-fitting products that are not useful to the user.

In practice it:

Design thinking can be considered at each of the discrete stages of design, requiring approaches to be adapted to where in the iterative cycle of developing an innovation the service or product is. The graphic below highlights the different stages of design and provides adaptable examples of how to involve design thinking within each stage.



Design thinking stages



Understand what is important through strength-based questions, journey mapping, storytelling and experiential design.

Co-design a problem statement and develop criteria for success with CYP using journey mapping, storytelling and reflections.

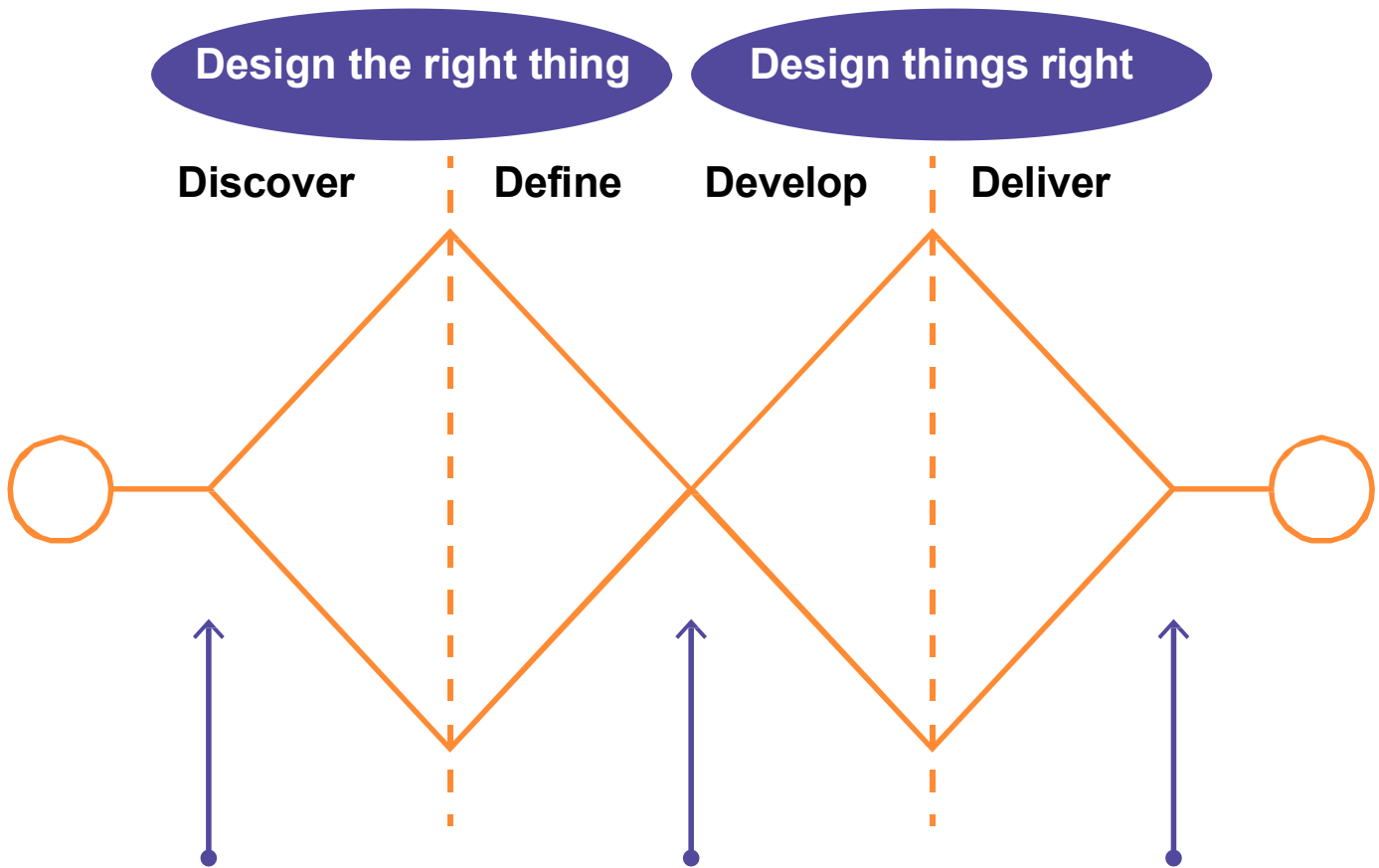
Get creative with activities for CYP to draw, craft or conceptualise their ideas for addressing the problem, using accessible formats.

Present prototype options to CYP, with CYP performing a run-through of how they may use and interact with the product/service

You can use think-aloud testing with CYP to surface confusion, stress-points, inaccessible features and potential bias, ensuring feedback is acted on and revisited where needed

The Double Diamond

The Double Diamond is an alternative method to visually represent the process of design and innovation. It can help demonstrate steps taken, including where advisory input from people with lived experience can support the process.



Problem: Start with identifying the problem. Here, you can involve lived experience to understand key priorities through creative storyboarding, unstructured/semi-structured focus groups, and mind-mapping.

Definition: Turn insights into shared understanding of the problem and start exploring possible opportunities to address the problem through co-design of prototypes. Involve lived experience experts in creating prototypes.

Solution: Involve users by testing solutions in real-world settings, providing feedback on usability and experience, and contributing to iterative refinements so the final product is validated, improved, and practical to implement.



Innovator case study - Tellmi

tellmi

How does Tellmi support ND CYP?

Tellmi is a digital peer support and wellbeing app where young people can safely share experiences and access support around mental health. Tellmi supports high numbers of neurodivergent users, with 18% reporting a diagnosis of autism and 14% ADHD.

How does Tellmi approach user-centred design?

Tellmi continuously involves young people with lived experience through in-app feedback, co-design workshops and a Youth Advisory Board, many of whom are neurodivergent. Youth input has shaped the app's tone, safety features, moderation, user experience and wider service development, demonstrating how user voice can be embedded throughout.

In 2025, Tellmi worked with autistic young people to co-develop a specialist support extension, including an interactive digital safety plan and resources on topics such as sex and relationships, identified by young people as overlooked by other services.

Find out more

<https://www.tellmi.help/>

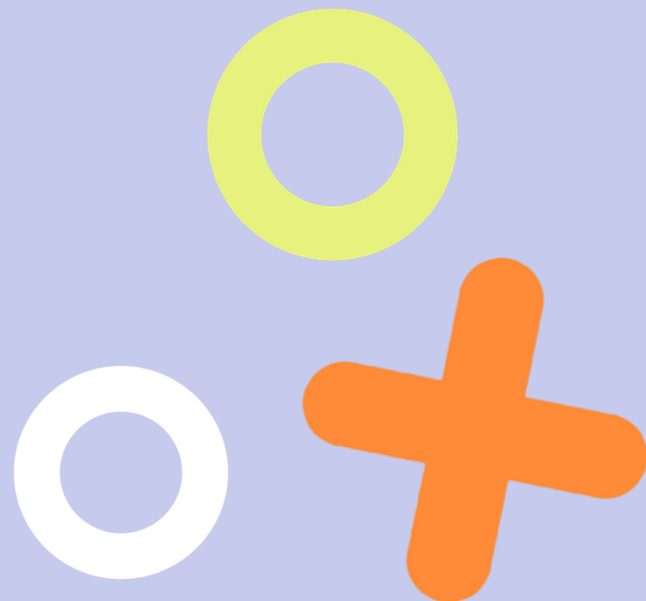


Child Rights by Design

Child Rights by Design is a set of rights-based principles that inspires innovators to design for children's rights. Grounded in the [United Nations Convention on the Rights of the Child \(UNCRC\)](#), these principles can be used by innovators to map how their product or service meets these rights, supporting development of equitable, responsible and impactful innovation.

Whilst these principles are built for children of all neurotypes, we have demonstrated how each principle in the framework may be addressed when designing with neurodivergent CYP in mind and when involving them in the design process.

We also recommend consulting the **5 Rights Foundation's** new [Children and AI Design Code](#) which has just been launched; CYP rights, safety and privacy are put front and centre.





Innovator case study - Zendra Health

How does Zendra Health support ND CYP?

Zendra Health connects clinicians, patients, parents, and teachers to deliver more efficient, effective, and safer neurodevelopmental assessment, treatment, and medication monitoring at scale.

How does Zendra Health approach user-centred design?

Engaging in user-centred design, a multi-stakeholder design-thinking workshop brought together parents, clinicians and educators to explore lived experience, identify system challenges and co-create solutions.

Insights informed the development of a prototype digital tool now being implemented in clinical settings, demonstrating how multi-stakeholder co-design is vital for pathway-level innovation and structured design-thinking supports shared understanding.

Find out more

<https://www.zendrahealth.com/>



Child Rights by Design

Equity and diversity

Ensure ND CYP are represented throughout design and that sensory and communication barriers are actively removed. Adopt an intersectional approach to neurodiversity and acknowledge unconscious bias.

Best interest of the child

Prioritise autonomy, dignity and regulation over compliance, recognising that calming, supportive approaches look different for each child. Include CYP and families (if involving young children) in the planning to ensure their interests are at the heart.

Consultation

Engage neurodivergent children meaningfully, not symbolically. Use flexible, accessible methods (e.g. visual tools, creative opportunities, movement, digital input) and allow time for processing and reflection.

Age-appropriate

Design for both chronological age and developmental profile. Avoid infantilisation by using clear, literal communication and offering scaffolded support rather than oversimplifying content.

Responsible design

Design ethically with awareness of sensory, cognitive and emotional impact. Avoid overstimulation and features that exploit hyperfocus and consider neurodiversity impacts throughout development.

Participation

Enable meaningful participation in learning, play and decision-making. Offer alternative ways to contribute, reduce social pressure, and avoid relying solely on verbal communication.

Privacy

Respect the privacy of neurodivergent children by respecting if they prefer not to share within a group or with their real name. Avoid unnecessary disclosure of diagnoses, protect SEND data, and provide support spaces without stigma.

Safety

Safety may include reviewing physical spaces to prevent physical harm. Protect against sensory overload, social exclusion and online vulnerabilities, and create predictable environments that reduce anxiety and distress.

Wellbeing

Support emotional regulation and mental health proactively. Having familiar, trusted adults such as support workers, support group facilitators and youth workers can help and signposting to SEND/mental health professionals can provide additional support.

Development

Support diverse developmental pathways, with opportunities to value deep interests and specialist skills. Provide structure and overview of the process supporting executive-functioning.

Agency

Empower neurodivergent children to make choices about their involvement including environment, communication preferences, level of involvement and pace. Encourage self-advocacy and independence as much as possible.

The Lundy Model

The Lundy Model (2014) is a framework for understanding and supporting children and young people. It can be used to identify strengths and gaps in participation processes when planning.

Its four elements are:

- **Space:** create supportive environments for participation
- **Voice:** include the relevant young people and reduce barriers to sharing their perspectives
- **Audience:** consider who is listening to CYP and where their voices reach
- **Influence:** ensure the participation is meaningful and impactful



Applying the Lundy Model

Space

- Create sensory-friendly, familiar environments
- Have a clear structure, trusted facilitators, and flexible ways to take part
- Allow alternative ways to participate
- Be adaptable to create opportunities to engage comfortably and confidently.

Voice

- Proactively include neurodivergent children and young people from diverse backgrounds
- Use clear, accessible information, child-friendly and neurodiversity-affirming language
- Think about creative methods, and time for reflection and rest.

Audience

- Ensure the right people are listening by being clear who decision-makers are
- Show how young people's views will be shared, and how their input fits into wider decision-making
- Have clear feedback and communication loops.

Influence

- Make participation meaningful by showing how views have shaped decisions or designs
- Provide opportunities for CYP to be partners in projects
- Share outcomes in accessible formats
- Work with CYP to promote their contribution and how they have been involved

Levels of engagement

When thinking about how to involve lived experience, there are different levels of engagement that can be considered based on the insights you are looking for. Levels of involvement in design can be understood as a continuum – from informing decisions to shaping and leading them – with increasing power-sharing between innovators and lived experience groups. This reflects a core user-centred design principle: recognising children and young people as active contributors rather than end-users. An example of this is [Allison Druin's framework](#) which helps operationalise this by describing roles such as user, tester, informant, and design partner, which can be selected based on the aims and needs of a project.

Innovator case study - Cogs AI



How does Cogs AI support ND CYP?

Cogs AI is a neurodiversity-specific emotional wellbeing app designed to manage and prevent burnout, strengthen mental fitness and identify key triggers, supporting young people through personalised self-care plans, reflection tools and self-regulation techniques.

How does Cogs AI approach user-centred design?

Neurodivergent young people are involved through interviews, focus groups, hackathons and research partnerships. Involvement is designed to be accessible and sustainable, including valuing lived expertise equally to learned experience. Cogs AI employed neurodivergent young people aged 16+ on paid internships to work with the product team and influence the design of the app. User feedback has led to major project changes, including the decision to not employ gamification as a feature in the app, instead designing more flexible, modular tools.

Find out more

<https://www.cogs-ai.com/>

Levels of engagement

From one-way involvement to equal partnership



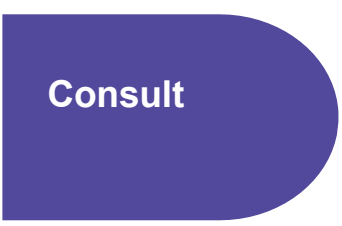
Lived experience is given equal partnership in design from idea conception to output. Commitment to gold-standard co-production is lengthy and resource-intensive; it may require specific staffing needs within the organization to coordinate participation.



A collaboration for working together to include everyone's ideas in a design. It might involve questions, creative activities, providing feedback and reviewing resources. It requires robust feedback loops, resources and support to ensure accessible participation



An informal approach to listening and understanding what people want, key issues and ideas for change. May be semi-structured around certain concepts or projects but enables discussion. Helpful for understanding need but may only influence change indirectly.



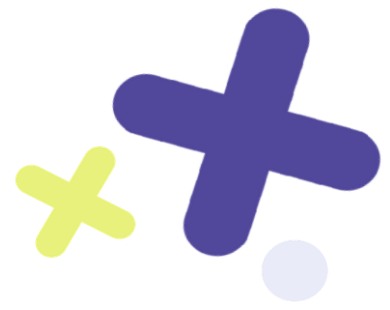
When consulting, you may gather opinions or feedback on certain ideas or products through question and answer, via individual meetings, surveys or focus groups. May not change direction or shape of outcomes.



This involves sharing information about what you are working on, keeping people updated on project progress and highlighting any changes made. It is not led by lived experience, and participants have no influence on decisions.



Learning from neurodivergent young people



How do neurodivergent young people want to be involved?

We worked with neurodivergent **youth partners at Surrey County Council** to understand young people's perspectives on user-led design and how they want to be involved in the process. Their lived-experience insights have shaped this resource and strengthened its credibility and relevance.

The importance of innovation

- Young people valued innovation that addresses everyday challenges by reducing anxiety, effort, or exclusion
- Innovations were seen as positive when they supported independence, reduced feelings of isolation, and fitted into daily life
- New products were more trustworthy if they had been developed in partnership with people like them
- Evidence-based innovation was particularly favoured.

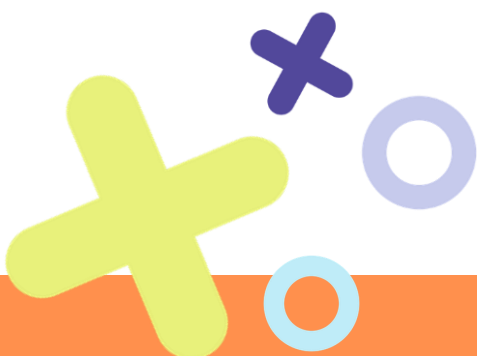


Creating opportunity for user-centred design

- Young people wanted to be involved from idea generation through to creation, valuing iterative engagement with multiple rounds of testing
- They appreciated the opportunity to genuinely influence decisions throughout the process rather than in a tokenistic manner
- Being informed how input is incorporated contributed to feeling important and valued in the process
- There was strong interest in working directly with developers, contributing to creative decision-making and learning how design choices are made
- Young people wanted to be involved from idea generation through to creation, valuing iterative engagement with multiple rounds of testing, rather than one-off sessions, although preferences varied.

Barriers to user-centred design

- Young people were fearful of experiencing judgement, rejection and bias against them
- Some past experiences suggested feedback had been ignored and promised adjustments were not followed through
- Unclear and inaccessible processes further undermined engagement such as a lack of agendas, inaccessible language and uncomfortable environments
- Young people were also critical of tokenistic or narrowly defined involvement, such as consulting small groups, or where intersectionality and different support needs are not represented.



Key quotes from young people

“Having a clear focus on offering real beneficial support for young people.”

“Providing obvious reason for using the app to not over complicate things.”

“I like how they had an 8-week testing. They were clearly wanting to make sure it was developed around the needs of the target audience”

“I think it would be quite cool to actually be able to work with the developers.”

“I think it would be great if there was a 6 month check in after the workshops to see if there’s anything else that needs adapting.”

“They may be discouraged if their feedback hasn’t been implemented in the past, so maybe reassurance that they’ll be taken seriously will help.”

“One person can’t give you an accurate representation of a wide range of people’s experience.”

“Not being given specific instructions or questions being worded in an inaccessible way.”



Recommendations for user-centred design with neurodivergent children and young people



Principles for implementation

Drawing on theory, lived experience and examples from practice, we developed guiding principles for user-led design with neurodivergent young people to promote a consistent foundation for inclusive engagement.

Key principles:

- A strength-based and intersectional approach to neurodiversity
- Leadership & partnership
- Active participation across design phases
- Power-sharing and fair compensation
- Creating safety by design
- Continuous, transparent, and ethical involvement



A strength-based and intersectional approach to neurodiversity

- Take a strength-based approach that recognises neurodivergent strengths such as creative problem-solving, systems thinking, attention to detail, and authenticity
- Acknowledge diversity, avoiding assumptions of a single or universal lived experience for all neurodivergent people
- Include a wide range of neurodivergent voices, including autistic, ADHD, dyslexic, dyspraxic, Tourette's and multi-profile individuals
- Design with intersectionality in mind, recognising how identity, experience and context shape needs and perspectives

Leadership & partnership

- Neurodivergent individuals can be involved as co-designers, co-researchers, and co-decision makers
- Representation in governance and steering groups is key to ensure innovations are based on lived experience not only learnt experience
- Shared authorship and ownership present opportunities for neurodivergent people to create, gain new skills and reduce transactional involvement

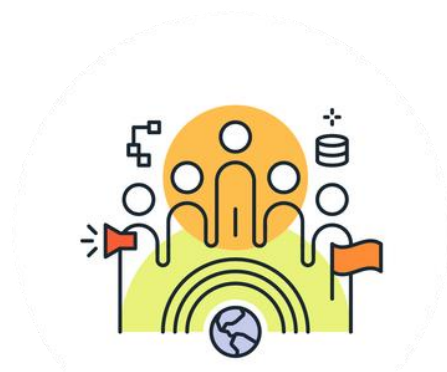


Active participation across design phases

- Co-explore needs, barriers and opportunities through lived-experience-led inquiry within background research and exploration
- Shape problem statements and project success criteria with neurodivergent CYP, grounded in real-world insight rather than assumptions
- Collaborate with CYP to generate and refine ideas using accessible, flexible methods that support different communication styles
- Co-create early prototypes using low- to high-fidelity formats to test usability, accessibility and emotional impact in safe ways
- Iteratively test and refine solutions with CYP, using feedback loops to shape delivery, communication and long-term impact.

Power-sharing and fair compensation

- Paying lived experience as professional expertise sees young people's engagement as valuable contribution
- It is important to show how transparent decision-making is, showing where CYP's decisions are being included, how they have been considered and if they are not, showing why
- Co-own outputs where appropriate, such as naming young people as collaborators, co-authors, co-designers.



Creating safety by design

- Ensure psychological, sensory and social safety are built into processes, such as flexible pacing of meetings, alternative communication mechanisms, and trauma-informed, neuro-inclusive facilitation
- Ensure clear, concrete jargon-free language, and multiple options for communication
- Create predictability in agendas, structures and expectations, setting out as much detail prior to involvement as possible to reduce cognitive stress
- Modify design activities to reduce cognitive or sensory load, such as allowing reflection time, individual contributions, and alternative formats, reducing pressure for rapid consensus or heavy social interaction.

Continuous, transparent, and ethical involvement

- Good involvement can look like consistent engagement from start to finish, such as regular check-ins with advisory groups or design communities for sense-checking
- Introduce the ability for CYP to review and withdraw input and contribute to the shaping of the involvement itself
- Involve CYP to understand what value and success looks like for a product or service that aims to support them.



Neurodiversity user-centred design checklist

Using this checklist

This checklist is intended as a reflective and improvement tool, not a tick-box exercise, to help innovators think about how to plan and establish user-centred design in their work. Not every project will reach full co-production levels, but all should be transparent, proportionate and meaningful.

Revisiting this checklist at multiple points in the innovation lifecycle can help ensure user-led design remains authentic, ethical and impactful and will be most effective if trialed and adapted to the ways of working within individual projects and organisations.



Neurodiversity user-centred design checklist

- Is there a clear, meaningful reason for involving neurodivergent children and young people (ND CYP) such as shaping decisions, contributing expertise or collaborating?
- Where in the process are ND CYP involved, and are they engaged as co-designers, co-researchers, decision-makers or consultees?
- Is the level of participation clear and proportionate, with transparency about how influential lived experience is in the design process?
- Is power shared where possible and are ND contributors compensated and recognised for their time?
- Does involvement reflect the true diversity within neurodivergent populations, actively valuing different strengths, profiles and intersectional experiences?
- When communicating, is communication clear, jargon-free and accessible, with multiple ways to engage?
- Does involvement prioritise autonomy and dignity, through trauma-informed, neuro-affirming approaches?

[Download checklist](#)



Final reflections

This guide aims to position user-centred design with neurodivergent children and young people as a priority within innovation, whether developing services or new digital products. Meaningful involvement is most effective when lived experience is treated as expertise, participation is designed to be accessible by default, and young people are involved early and throughout the innovation lifecycle.

By combining youth voices, practical frameworks and real-world case studies, this guide aims to support innovators to move beyond tokenistic engagement towards approaches that are ethical, inclusive and impactful.

The principles and checklist included are intended to be used flexibly, adapted to context, and revisited over time as relationships, understanding and trust develop, rather than in a prescriptive manner. Trialing and adapting these tools to suit your organisation and each individual process is key in establishing longevity of these methods within your work. We encourage teams to see user-led design not as an additional requirement, but as a core part of responsible innovation, one that strengthens outcomes for young people, families and systems alike.



Further information

If you or your organisation would like to get in touch with **Health Innovation Kent Surrey Sussex**, please visit our website and fill out our enquiry form healthinnovation-kss.com/contact-us/. If you have any questions specifically relating to this guide, please direct your enquiry to the **Translational Research Team**.

Acknowledgements

We would like to thank young people who attended our focus group in partnership with Surrey County Council. Their insight through lived experience was central to shaping this guide, and we would like to extend our thanks to the staff who helped facilitate the group. We are grateful to the innovators who shared their learning and practice, and we would welcome further collaboration with innovators in this space. We also thank colleagues across the wider health innovation network and the Office for Life Sciences for supporting this work.

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