What Good Looks Like

Patient Empowerment, Shared Decision-Making, Psychosocial Care and Transition

Across the life course

Ready Steady Go programme

TIER Transition & Patient Empowerment Innovation, Education & Research Network

UKKA UK Kidney Association

Version 1.0

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What Good Looks Like: Patient Empowerment, Shared Decision-Making, Psychosocial Care and Transition

(for Young People and Young Adults with Kidney Disease)

Developed with clinical leadership and formal endorsement from the UK Kidney Association Transition / Young Adult Specialist Interest Group.

A consensus framework to standardise practice, support improvement and enable benchmarking.

Co-produced with patients, families, patient charities and delivery partners, including RSG TIER, part of the Ready Steady Go Hello programme.

Foreword

Young people and young adults living with kidney disease experience some of the most complex transitions in healthcare. Alongside changes in health and treatment, they are navigating education, employment, relationships, independence and identity. During this period, how services support preparation for transition, communication and involvement in decisions has a lasting impact on engagement, experience and outcomes.

This framework sets out “what good looks like” for transition, patient empowerment, shared decision-making and psychosocial care in kidney services. It recognises transition as a developmental process rather than a single transfer event, and places shared decision-making and empowerment at the centre of safe, high-quality, person-centred and sustainable kidney care.

The framework is intended to support reflection, quality improvement and benchmarking across services, while remaining flexible to local context. It focuses on outcomes and experience rather than prescribing service models, staffing structures or specific tools. Its purpose is to reduce unwarranted variation, support consistent good practice and enable shared learning across the kidney community.

This framework has been collaboratively developed through an iterative, consensus-based process with broad agreement, supported by national stakeholder engagement, including UK Kidney Association Special Interest Group leadership, with contributions from patients, families, charities and delivery partners. It draws on practical experience of embedding structured preparation, meaningful conversations and measurable

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shared decision-making into routine care, while maintaining a collaboratively developed, RSGH-led standards framework that is intentionally tool-agnostic to support flexible, wider adoption across services, informed by UKKA priorities.

Although rooted in transition from paediatric to adult services, the principles set out in this framework extend across the life course. Patient empowerment and shared decision-making remain essential within adult and older-adult services, where needs, priorities and circumstances continue to evolve over time. Supporting these principles throughout adulthood is fundamental to sustained engagement, informed choices and high-quality, sustainable long-term outcomes for people living with kidney disease.

The framework also recognises the value of shared learning and co-production across paediatric and adult services, particularly in developing resources that are accessible, sustainable and responsive to real-world health literacy needs.

Together, these principles aim to strengthen person-centred kidney care and support a consistent, high-quality experience for all people as they move through the healthcare system.

Although developed within kidney services, the principles set out in this framework are transferable across long-term conditions, supporting wider consistency, shared learning and high-quality person-centred care.

The framework aligns with national standards and recognised clinical governance frameworks, ensuring consistent, accountable and benchmarkable practice across services.

The framework builds on the established RSGH standards foundation, supporting continuity, coherence and sustainable wider use.

Shared Decision-Making: The SIG Perspective

The UK Kidney Association Young Persons and Young Adult Specialist Interest Group views shared decision-making as a core part of good kidney care across the life course rather than an additional task or one-off conversation.

From diagnosis – whether in infancy, childhood, adolescence or adulthood, shared decision-making supports preparation, confidence and meaningful involvement over time, helping care to reflect what matters to people and families as lives, priorities and circumstances change.

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Shared decision-making is strengthened through structure, continuity and supportive relationships, and forms a foundation for safe, person-centred and sustainable care from early childhood through adulthood and into older age.

When embedded consistently, shared decision-making ensures that evolving needs and preferences are recognised, respected and incorporated into routine care.

Quick Guide: What Good Looks Like for Transition, Shared Decision-Making and Person-Centred Care Across the Life Course

In this framework, “transition” is understood as a continuous, empowerment-based process that occurs across the life course – from infancy and childhood through adolescence, adulthood and older age. It reflects how people adapt to changing health needs, priorities and circumstances over time. These Good Practice Standards therefore apply beyond paediatric–adult transfer and support care for people of any age living with long-term conditions, including adults newly entering services.

Together, the 15 Good Practice Standards outline the core components of high-quality, person-centred care: developmentally appropriate preparation; evolving conversations; clear and respectful communication; personalised pathways; proactive psychosocial support; supportive follow-up of missed appointments; coordinated team working and proportionate measurement for learning and improvement.

Inclusive Transition: Learning Disabilities, SEND and Additional Needs

Transition must work for all young people, including those with learning disabilities, SEND and additional needs.

This is not a separate pathway. It is core to good care.

Care should be accessible, developmentally appropriate and supported by reasonable adjustments.

Young people should be supported to take part in decisions at a level that works for them, with family involvement where needed.

These principles apply across all standards.

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WHAT GOOD LOOKS LIKE: The 15 Good Practice Standards

GP1 - Early Preparation

Transition preparation begins from **11–12 years**, or at diagnosis if later.

GP2 - Embedded in Routine Care

Transition is a routine, shared responsibility across paediatric, adult and primary care.

GP3 - Regularly Revisited

Transition is discussed early and revisited over time as needs, understanding and circumstances evolve.

GP4 - Developmentally Appropriate Care

Supports autonomy at a pace appropriate to the patient's developmental stage.

GP5 - Shared Decision-Making (SDM)

Decisions are made with the patient, with support for understanding and family involvement where needed, using structured SDM approaches.

GP6 - Letters Written to the Patient

All clinical letters are written directly to the patient in clear, respectful language, with copies to parents, carers or the MDT when needed.

GP7 - Personalised 16+ Pathway

Describes where adult care will sit, who will be responsible, and how decisions will be made.

GP8 - Information About Adult Services

Provides clear, developmentally appropriate and reusable information about adult services.

GP9 - Joint Working

Joint paediatric–adult clinics or early, structured collaboration.

GP10 - Planned Transfer

The timing of transfer is planned, agreed, and clearly communicated to all teams.

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GP11 - Place-of-Care Policy (16–18)

Services have a clear 16–18 place-of-care policy to prevent young people falling between services.

GP12 - Non-Attendances = Unmet Need

Missed appointments trigger supportive re-engagement.

GP13 - Psychosocial Support & Participation

Proactive identification of psychosocial needs; support for education, training, employment and participation.

GP14 - Apply to All Young Adults

All standards apply to young adults, including those newly presenting to adult services.

GP15 - Measure for Improvement

Preparedness, shared decision-making, continuity and psychosocial support are measured proportionately.

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Good Practice to Guidance Mapping Table

The table below shows how each Good Practice Standard connects to the Implementation Guidance - helping you see which sections can support delivery in your own practice and guide your next steps.

Good Practice (GP) Standard	Implementation Guidance (IG) Section(s)
GP1 – Early Preparation	IG1, IG2.1
GP2 – Embedded in Routine Care	IG1, IG6
GP3 – Regularly Revisited	IG1, IG2.1
GP4 – Developmentally Appropriate Care	IG1, IG3
GP5 – Shared Decision-Making	IG3, IG4
GP6 – Letters Written to the Patient	IG3, IG6
GP7 – Personalised 16+ Pathway	IG2.1
GP8 – Information About Adult Services	IG2.2
GP9 – Joint Working	IG2.2, IG6
GP10 – Planned Transfer	IG2.1, IG6
GP11 – Place-of-Care Policy (16–18)	IG2.2

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GP12 – Non-Attendance = Unmet Need	IG5, IG6
GP13 – Psychosocial Support & Participation	IG5
GP14 – Apply to All Young Adults	IG6
GP15 – Measure for Improvement	IG7

Purpose and Scope

This document sets out what good looks like for transition, shared decision-making and psychosocial care for young people and young adults with kidney disease, typically aged 11–30 years. While centred on this group, the principles also support people living with long-term conditions across the life course.

It is intended to:

- support safe, consistent transition from paediatric to adult-oriented care
- embed shared decision-making as routine practice rather than reliance on individual practice
- recognise psychosocial wellbeing as integral to high-quality kidney care
- improve experience, engagement and continuity, and enable services to evidence, benchmark, and share learning
- align local practice with national quality indicators

The framework aligns with the remit of the UK Kidney Association Special Interest Groups, particularly in relation to measurement, implementation, improvement and education.

This framework is outcomes-focused and tool-agnostic. It does not mandate service models, staffing arrangements or specific tools.

This document also supports delivery of the *What Good Looks Like* framework by setting out the key components and enablers that kidney services need to implement and evidence high-quality transition, patient empowerment and shared decision-making in practice.

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It recognises that achieving good outcomes requires more than isolated tools or one-off initiatives. Instead, it depends on structured, longitudinal approaches that support preparation, conversation, documentation and continuity over time.

The implementation sections translate principles into practical components that services can use to support consistent delivery, reflection and improvement. It aligns with national approaches to transition, patient empowerment and shared decision-making, and supports services in demonstrating high-quality, person-centred care.

The implementation guidance should be viewed as a **living resource**, evolving as services share examples, tools and learning from implementation.

The principles outlined in this document are consistent with national guidance on patient experience, shared decision-making and transition, supporting person-centred care and meaningful involvement of young people in decisions about their health.

How to Use the Implementation Sections

These do not redefine what good looks like. Instead, they describe the practical components and enablers that services need in place to deliver the standards set out in this *What Good Looks Like* framework. Sections will cover different Good Practice Standards and implementation components.

The aim of these sections is helping services identify:

- what is already in place
- what may be missing
- where to focus improvement efforts

Practical “how-to” guidance and worked examples are signposted throughout this document using example resource boxes.

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Box Legends Used in This Document

This document uses several types of highlighted boxes to support implementation.

What good looks like in practice
Key features commonly seen in services delivering this element of the framework.

Example resource
Illustrative tools or examples that services may use or adapt.

Worked example
Practical examples showing how elements of the framework may be delivered.

Where to start
Practical steps services may take when beginning implementation.

These examples are illustrative and are not mandated.

Some resources are referenced in multiple sections because they support several aspects of transition, shared decision-making and patient empowerment.

Core Principles

Good transition and shared decision-making:

- begins early and develops over time
- recognises young people as emerging adults
- supports increasing autonomy at an individual pace
- prioritises engagement, experience and safety
- recognises psychosocial wellbeing as integral to care
- requires collaboration across paediatric, adult and primary care teams

These principles apply throughout the life course. Patient empowerment and shared decision-making remain essential within adult and older-adult services where needs, priorities and circumstances evolve over time.

Transition and shared decision-making are **processes, not events**.

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They require:

- repeated, age-appropriate conversations
- preparation before appointments
- opportunities to revisit and reflect on decisions
- continuity across paediatric, adult and primary care services

Without a structured approach, transition preparation and shared decision-making risk becoming inconsistent, clinician-dependent, difficult to evidence and vulnerable to service change.

"It wasn't one conversation that helped - it was being supported over time and being asked again as things changed."
-Young person

The following Good Practice Standards set out what high-quality transition, shared decision-making and person-centred care look like in practice.

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Good Practice 1 - Early Preparation

Transition preparation should typically begin from 11–12 years of age. For those diagnosed later, preparation should begin at the point of diagnosis regardless of age.

Why This Matters

Starting the transition process early allows understanding, confidence and shared decision-making skills to develop gradually rather than being rushed at the point of transfer.

Early discussions allow young people to understand how their care will change over time and help families and clinical teams prepare for transition in a structured way.

Starting transition preparation does not imply early transfer to adult services.

Preparation for transition should be early, gradual and developmental.

Services delivering good practice **actively prepare patients and families for their care and can demonstrate that preparation and orientation are embedded within routine care.**

Preparation begins in early adolescence and continues throughout transition. As young people approach adulthood, discussions about future care arrangements become more explicit.

From around **16 years of age**, services should support structured discussions with young people and families about where future care will be delivered and how transition to adult services will occur.

These discussions should be revisited over time as needs and circumstances change. Decisions about future care arrangements should be made **in partnership with the young person and family and documented clearly in the transition plan.**

Orientation resources then help young people and families understand how services work and who will be involved in their care as they move towards adult-oriented services.

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Good Practice 2 - Embedded in Routine Care

Transition preparation is embedded within routine clinical care and is a shared responsibility across paediatric, adult, primary care, community and specialist teams.

Why This Matters

When transition is seen as everyone's business, young people experience fewer gaps and less variation in care.

Where to start: practical steps services can take

Services do not need to implement every element of the framework immediately.

Many teams begin with a small number of practical changes that support patient empowerment and shared decision-making.

Examples include:

- introducing **a structured preparation framework** for transition
- making **shared decision-making prompts visible** in clinic areas (e.g. Ask 3 Questions posters)
- ensuring **clinic letters are written directly to the patient**
- signposting young people to **peer support or youth groups**
- introducing simple **Meet the Team orientation resources**

These small steps can improve patient experience immediately while services develop more comprehensive approaches over time.

Using a Framework to Deliver Patient Empowerment

Services delivering high-quality transition support, patient empowerment and shared decision-making can usually demonstrate that a structured framework is in place to support delivery.

A framework provides the scaffold for **consistent transition support, patient empowerment and shared decision-making over time**, rather than relying on isolated tools or individual clinician practice.

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What good looks like in practice – structured frameworks

Services can usually demonstrate that a structured framework supports:

- preparation from early adolescence
- progressive development of understanding and independence
- repeated shared decision-making conversations
- integration of psychosocial considerations
- continuity across paediatric and adult care
- documentation that reflects conversations and decisions over time

Evidence may include preparation tools, patient-facing resources or service review using the self-assessment checklist.

Why This Matters

A structured framework supports consistent transition preparation, patient empowerment and shared decision-making across services.

It helps ensure conversations, preparation and follow-up occur routinely over time rather than depending on individual clinicians or isolated consultations.

Frameworks also support continuity of care and allow services to document, review and improve practice.

Practical tools, worked examples and links to shared decision-making resources are highlighted throughout this guidance in shaded example boxes. Services may also wish to refer to the references listed at the end of the document for further detail or supporting evidence.

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Example resources – structured frameworks

Illustrative examples of structured approaches include:

- **Ready Steady Go Hello (RSGH)** – a co-produced transition and patient empowerment programme used across long-term conditions *www.readysteadygo.net*
- **Conversation prompt tools** that support shared decision-making in consultations, such as **Ask 3 Questions** *Shared Decision-Making & Ask Three Questions - TIER Network*
- **Decision-specific shared decision-making pathways**, for example dialysis modality choice frameworks described in the kidney care literature: *https://ep.bmj.com/content/edpract/early/2024/06/26/archdischild-2023-325513.full.pdf*
  Nagra A, Fuller ID, Connett G et al. Empowering children, young people and families through shared decision-making: a practical guide.

Services may use different frameworks provided they align with the principles set out in **What Good Looks Like**.

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Good Practice 3 - Regularly Revisited

Transition is discussed early and revisited regularly so young people and families understand what to expect.

Why This Matters

Gradual preparation reduces anxiety, supports confidence and improves engagement.

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Good Practice 4 - Developmentally Appropriate Care

Care is developmentally appropriate, encouraging independence while recognising individual readiness.

Why This Matters

Young people should be supported as emerging adults. Supporting autonomy at the right pace strengthens shared decision-making and long-term self-management. Some young people, including those with learning disabilities or SEND, may need additional support to take part in decisions. Autonomy should be supported at an individual pace, with reasonable adjustments where needed.

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Good Practice 5 - Shared Decision-Making

Decisions are made with young people, with open discussion of options, risks and preferences. Discussions should be adapted where needed, with family involvement where appropriate, while keeping the young person's voice central. Structured tools such as *Ask 3 Questions* can support these discussions by helping young people prepare, understand their choices and participate more actively in decisions.

Why This Matters

Shared decision-making should be the default. Shared decision-making improves understanding, adherence, trust and engagement.

Ensuring that young people are actively involved in decisions about their future care supports confidence, empowerment and engagement with services and continuity of care.

Services delivering effective shared decision-making can usually demonstrate that conversation-supporting resources are routinely used, rather than relying solely on ad hoc discussion.

Shared decision-making is a **process, not a single conversation**. Resources should support:

- preparation before appointments
- meaningful dialogue during consultations
- reflection and follow-up afterwards

Examples of conversation-supporting resources may include:

- question prompt lists
- visual aids explaining options, risks and benefits
- comparison tables or decision grids
- preparation tools used before clinic

Use of these resources should be visible in practice, for example through documentation of preparation, reference to tools used, or patient-reported experience of involvement in decisions.

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What good looks like in practice: shared decision-making conversations

Conversation resources can help young people and families prepare for discussions and participate more actively in decisions about their care.

Examples may include:

- **Ask 3 Questions** (core prompt tool supporting shared decision-making)
- question prompt lists
- visual aids explaining options and risks
- comparison tables or decision grids
- preparation tools used before clinic appointments

These resources may be visible in:

- clinic rooms
- waiting areas
- digital check-in screens
- patient portals

Making these tools visible and accessible can help prompt questions, support understanding and strengthen shared decision-making conversations.

Why This Matters

Shared decision-making supports young people and families to understand their options and participate actively in decisions about their care.

Using structured conversation tools helps normalise questions, improves understanding and supports more balanced discussions between clinicians, young people and families.

Embedding shared decision-making within routine care improves patient experience, strengthens engagement and empowerment, and helps ensure decisions reflect what matters most to the young person. This can also improve understanding, support adherence to agreed plans and reduce conflict or uncertainty around care decisions.

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Example resource: Ask 3 Questions

Ask 3 Questions is a simple conversation prompt that supports shared decision-making by encouraging patients to ask three key questions during consultations.

Patients are encouraged to ask:

- **What are my choices?**
- **What's good and bad about each choice?**
- **Who can help me make a decision that is right for me?**

This tool can be used before, during or after consultations to help young people and families prepare for discussions, understand options and participate more actively in decisions about their care.

Resource:
https://www.readysteadygo.net/shared-decision-making--ask-three-questions.html

This example illustrates how simple prompts can support shared decision-making conversations and encourage patients to take an active role in decisions about their care.

Example resources – transition preparation

Illustrative examples may include:

- Ready Steady Go Hello transition preparation tools
- orientation resources introducing adult services
- shared decision-making conversation prompts (for example Ask 3 Questions)
- **peer or "buddy-up" approaches**, where young people approaching transition can speak with others who have already moved to adult services

These approaches can help young people feel more confident, reduce anxiety and support preparation for adult care.

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Visibility in Patient Contact Areas

The Specialist Interest Group recommends that shared decision-making prompts, such as Ask 3 Questions, are visible in patient contact areas (for example clinic rooms, waiting areas or digital check-in screens). This helps normalise shared decision-making, encourages patients to ask questions and supports a consistent culture across teams and services.

How Services can Evidence this in Practice

Services may demonstrate delivery of shared decision-making through:

- confirmation that shared decision-making prompts are visible in patient contact areas
- documentation within clinical records that preparation or question-prompt tools were used
- patient feedback indicating they felt encouraged to ask questions and participate in decisions

This supports local reflection, quality improvement and alignment with national shared decision-making quality indicators without creating unnecessary burden for clinical teams.

Some decisions in kidney care are more complex and benefit from structured shared decision-making pathways that support discussion, reflection and informed choice over time.

Decision-specific Shared Decision-Making Pathways

Complex treatment decisions can benefit from structured shared decision-making pathways.

In kidney care, structured approaches are often used to support complex treatment decisions. For example, dialysis modality choice discussions may be supported through decision pathways that help young people and families understand options, consider preferences and make informed decisions over time.

These pathways support shared decision-making by providing a clear structure for discussion, reflection and documentation across multiple consultations.

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What good looks like in practice – decision pathways

Services can usually demonstrate that:

- complex treatment decisions are discussed over more than one appointment
- multidisciplinary team members contribute to discussions where appropriate
- patient-facing resources help explain treatment options
- options, benefits and risks are explained clearly
- discussions and decisions are documented in clinical records
- outcome measures or feedback mechanisms support reflection and improvement

Why This Matters

Complex treatment decisions can be difficult to understand and may have significant long-term implications for young people and families.

Structured decision pathways allow time for discussion, reflection and questions, helping young people and families develop a clearer understanding of their options and participate actively in decisions about their care.

They also help ensure that important decisions are made in a planned and informed way rather than during periods of crisis, supporting patient empowerment and shared decision-making outcomes.

This approach may be applied to a range of complex treatment decisions in kidney care; dialysis modality choice provides a practical illustration.

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Worked example – dialysis choices

Dialysis modality choice provides a practical example of how structured shared decision-making pathways can support complex treatment decisions in kidney care across the life course.

These discussions are typically supported through staged conversations over time, co-produced patient resources and opportunities for young people and families to reflect on options before decisions are made.

Practical renal-specific shared decision-making resources, including patient-facing videos and decision-support materials, can be accessed via: https://www.readysteadygo.net/renal.html

Additional dialysis-specific resources and implementation guidance are currently being developed and will be added as this guidance evolves.

An example of a **living shared decision-making resource**, which will continue to evolve as additional materials and examples are developed with patients, families and clinical teams, can be found here: https://www.readysteadygo.net/renal.html

This resource illustrates how shared decision-making tools and patient-facing materials can be developed, refined and updated over time to support clinical practice.

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Example – using lived experience in shared decision-making

Lived experience resources, such as patient and family stories, can help young people understand treatment options and feel more confident participating in decisions about their care.

Examples of feedback from young people, families and healthcare professionals include:

"The dialysis choice videos were really helpful. Seeing and hearing from other patients and mums made everything feel much less scary. I felt listened to, and my choice mattered."
- Young person

"The videos helped us understand the options and feel less anxious. Hearing from other families made a huge difference and helped us support our child to make a decision that felt right for them."
- Parent

"Using patient videos alongside structured shared decision-making helped young people feel heard and more confident in their choices. It changed the quality of conversations and made decisions feel genuinely shared."
- Kidney healthcare professional

These examples illustrate how lived experience can support shared decision-making in practice. Services are encouraged to gather and use feedback from their own young people, families and teams as part of routine care and improvement.

Services should measure whether young people and families felt informed, involved and supported when making complex treatment decisions.

Recommended approaches to measuring shared decision-making and service implementation are described in the measurement section of this guidance.

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Good Practice 6 - Letters Written to the Patient

Written communication about care, decisions and next steps should be written and addressed directly to the patient using clear, respectful and age-appropriate language. The multidisciplinary team and GP should be copied where appropriate.

Why This Matters

Writing directly to the patient improves health literacy, reinforces shared decision-making and supports ownership of care.

Services delivering high-quality care can usually demonstrate that communication and documentation actively support shared decision-making, rather than simply recording clinical decisions.

Clear, patient-centred communication and documentation help reinforce understanding, ownership and continuity across teams and over time.

Clear communication also supports health literacy by helping young people understand their condition, treatment options and care plans.

Documentation should reflect shared decision-making as a process, not just a final decision at a single point in time.

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What good looks like in practice – communication and documentation

Good practice may include:

- documenting the options discussed and any resources used to support decision-making
- recording patient priorities, preferences and questions raised
- reflecting key factors influencing decisions where relevant
- writing clinic letters directly to the patient using clear, accessible language (for example, “Dear Johnny”) – Appendix 1
- letters written directly to the patient should begin during transition preparation rather than only at the point of transfer
- copying the multidisciplinary team and GP where appropriate to support continuity of care

Clinic letters may summarise:

- options discussed
- resources used
- patient priorities and preferences
- agreed decisions and next steps
- follow-up plans

Where clinical terminology is used it should be explained in plain language where possible (for example, “You have high blood pressure, also called hypertension”).

Why This Matters

When communication and documentation are clear and patient-centred, they reinforce understanding, confidence and **patient empowerment**.

They also support continuity across paediatric, adult and primary care services, helping ensure that decisions remain visible, understandable and revisit-able as circumstances change.

Clear documentation reduces repetition and miscommunication and helps young people remain actively involved in decisions about their care.

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Example – lived experience

"Getting a letter addressed to me made it feel like my care was really about me, not just my condition."
- Young adult

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Good Practice 7 - Personalised 16+ Pathway

From around 16 years of age, young people should enter a clearly defined personalised 16+ pathway.

The 16+ pathway describes where their adult care will sit, who will be responsible and how decisions will be made. The pathway may involve:

- adult nephrology
- shared care with the GP
- GP-led care over time

Each 16+ pathway should involve shared decision-making with the young person.

The pathway should be understood by the young person, their families and their healthcare teams.

Why This Matters

Young people are entering a phase where care increasingly moves toward adult-oriented services.

The 16+ pathway provides a structured way to support and evidence shared decision-making about future care.

It enables timely discussions about where care may sit and supports early referral to relevant adult or community services, allowing adult teams to plan and accommodate new patients.

Early, documented decisions support continuity, reduce last-minute transfers and allow adult services to anticipate capacity and future care needs.

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Worked example – 16+ preparation pathway

Many services introduce a structured 16+ preparation discussion during the later years of paediatric care.

This discussion may include:

- reviewing the young person's condition and current care, discussing where future care will be delivered (for example adult nephrology, shared care, GP-led care or discharge where appropriate)
- introducing adult services and explaining how they work
- identifying additional support needs before transition
- discussing research participation or consent where relevant
- using the transition plan to record discussions, options considered and the agreed direction of travel

These discussions should develop over time and be revisited as understanding, preferences and circumstances change, rather than occurring as a single conversation.

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Good Practice 8 - Information About Adult Services

Information about the adult services should be clear, age-appropriate and reusable so young people can revisit it outside clinic appointments.

Orientation resources help patients understand:

- who is involved in their care
- what their roles are
- how services work together

Joint working between paediatric, adult and community teams may take place face-to-face or virtually depending on local services, geography and individual needs.

This is particularly helpful:

- during transition
- before first adult appointments
- during periods of change or uncertainty

Introducing orientation resources early, rather than at the point of first adult attendance, helps young people arrive better prepared and more confident when meeting new teams.

Services delivering good practice also help patients understand who is involved in their care and how services work together.

Meet the Team resources are a core enabler of preparation and orientation.
Knowing who is involved in care, what their roles are, and how they work together helps reduce anxiety, support trust and enable more meaningful conversations in clinic.

What good looks like in practice: orientation and "Meet the Team" resources

Services can usually demonstrate that:

- patient-facing orientation resources are available
- young people understand who is involved in their care
- staff roles are explained clearly
- orientation resources are introduced before the first adult appointment where possible
- teams provide clear explanations of how services work together

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Why This Matters

Knowing who is involved in care reduces anxiety, builds trust, supports meaningful shared decision-making and helps young people feel more confident attending appointments.

Understanding team roles supports trust, improves engagement and enables more meaningful conversations during consultations.

When patients know who they will meet and what to expect, they are more likely to ask questions, participate in discussions and feel empowered to take an active role in decisions about their care.

Introducing orientation resources early can reduce uncertainty during transition, minimise misunderstandings or conflict, and support a more positive patient and family experience.

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Example resources- Meet the Team orientation

Examples of orientation resources and transition materials developed by kidney services will be shared via the **Ready Steady Go Hello renal pages** and may also be highlighted through **UK Kidney Association (UKKA) Transition / Young Adult Specialist Interest Group resources.** Resources will continue to be added as services share examples and learning.
https://www.readysteadygo.net/renal.html

Examples from UK kidney services include:

- **Queen Alexandra Hospital** – adult team introduction videos
  www.porthosp.nhs.uk/departments-and-services/renal-young-adult-service

- **Bradford** – Meet the Team videos
  https://vimeo.com/693568411

- **Ulster**– MDT introduction videos
  https://youtu.be/GpLYmKd6eb4

- **Leicester** – transition resources
  https://www.youtube.com/watch?v=ccCNP0GNzTM

These examples illustrate different formats and approaches used by services. Content and style will vary depending on local resources, resources available and team preferences.

Resources do not need to be professionally produced. Simple approaches such as photos of team members with short descriptions of their roles, brief phone-recorded videos, or even a simple leaflet or text introduction can work well while services develop more comprehensive materials. Wherever possible, resources should be co-produced with young people and families to ensure they are meaningful and accessible.

Services are encouraged to adapt approaches that fit their local context and resources.

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Good Practice 9 - Joint Working

Young people should be seen where possible in a joint clinic between paediatric and adult teams (either face-to-face or virtual) as part of the 16+ pathway.

Where joint appointments are not feasible, early communication and engagement with adult services remain essential.

Why This Matters

Joint working builds confidence, shared understanding and smoother transitions.

Joint working between paediatric and adult services, including joint appointments or shared discussions, is considered best practice, particularly for young people with complex needs.

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Good Practice 10 - Planned Transfer of Care

Timing of final transfer is planned and communicated with the young person, their family and all healthcare teams including the GP.

Why This Matters

Transfer to adult services should be anticipated and discussed in advance, with appropriate information shared across services.

Planning future care arrangements in advance supports shared decision-making and helps avoid last-minute transfers to adult services.

This ensures knowing who is responsible for care at all stages and eliminates gaps in care during transfer.

Adult Services and Young People Presenting Directly to Adult Care

Shared decision-making and patient empowerment should continue within adult services and should not be assumed to end at the point of transfer.

Adult teams may support both young people transferring from paediatric care and those who present directly to adult services during adolescence or early adulthood without previous structured preparation.

Some young people may arrive in adult care having already participated in transition planning and shared decision-making discussions. Others may require additional explanation and support to understand their condition, treatment options and how adult services work.

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What good looks like in practice: adult services

- shared decision-making conversations continue after transfer
- young people are supported to understand their condition and treatment options
- adult teams recognise that some young people may present without prior preparation
- developmentally appropriate explanations and resources are available
- structured conversation tools support understanding and participation in decisions

Why This Matters

Young people entering adult services may be adjusting to new care environments, different expectations and increasing responsibility for managing their health.

Continuing shared decision-making and empowerment within adult services helps young people understand their treatment options, build confidence in managing their condition and participate actively in decisions about their care.

This continuity supports engagement with services, reduces the risk of disengagement after transition and helps young people develop the confidence and independence needed to manage their health in adult life.

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Example resources: adult empowerment and shared decision-making

Illustrative examples may include:

- structured conversation tools used in adult clinics
- patient-facing information explaining treatment options and follow-up pathways
- resources designed to support empowerment and shared decision-making in adult care

Examples may include approaches such as **Ready Steady Go Hello (RSGH)** tools adapted for adult services, alongside other locally developed or nationally available resources.

Example resource link:

Ready Steady Go Hello – adult empowerment resources
https://www.readysteadygo.net/rsg-hello-to-adult-services.html

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Good Practice 11 - Place of Care Policy (16–18)

There should be clear local policies regarding the place of care for young people between ages 16–18 years, irrespective of whether they are presenting for the first time or are already known to the team but being seen for an unrelated issue.

Why This Matters

Young people aged 16–18 may present to kidney services for the first time during the transition period. Without clear arrangements this group can risk falling between paediatric and adult services.

Clear arrangements reduce delays in care, prevent fragmentation between services and ensure young people receive timely and developmentally appropriate support.

A clear 16–18 place-of-care policy prevents young people from falling between teams and ensures responsibility for care is stable, appropriate and transparent.

Preparing Young People for Future Care Decisions (around age 16+)

From around 16 years of age, preparation for adult-oriented care typically becomes more explicit as young people and families begin structured discussions about future care arrangements.

This stage provides an opportunity to review the young person's condition, explore future care options and begin planning the move to adult services. Discussions should take place over more than one appointment and allow time for reflection and questions.

Decisions about future care arrangements, including where care will be delivered in adulthood, should be made in partnership with the young person and family and documented within the transition plan.

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What good looks like in practice – 16+ preparation

Services can usually demonstrate that:

- structured discussions about future care arrangements occur from around age 16
- young people understand where their future care will be delivered
- options for adult care are discussed openly with the young person and family
- young people and families are supported to participate in shared decision-making
- discussions about care location are revisited over time
- adult services are introduced before the first adult appointment where possible
- discussions and agreed plans are documented in the transition record
- feedback from the young person and family indicates they felt involved in the decision about future care
- a clear 16–18 place-of-care policy is in place locally so young people in this age range are seen by the appropriate team and are not bounced between paediatric and adult services

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Good Practice 12 - Non-Attendance = Unmet Need

Missed appointments should be recognised as potential indicators of unmet need, with active support for re-engagement. Around transition, information regarding missed appointments should be shared between paediatric and adult teams.

Why This Matters

Transition is a high risk time for kidney transplant failure, non-adherence to medications, and increased risk of cardiac death.

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Good Practice 13 - Psychosocial Support and Participation

Teams should:

- Proactively identify psychosocial needs
- Ensure young people know how to access support
- Recognise participation in everyday life as an important outcome
- Support young people to achieve their goals in education, training and employment

Why This Matters

Young people and young adults with kidney disease are at increased risk of mental health difficulties and social disadvantage, including challenges related to education, employment, independence and participation in everyday life.

Support may include youth work, psychology, social care, peer support or voluntary sector support depending on local provision.

Psychosocial wellbeing underpins engagement, shared decision-making and safe transition.

Supporting participation in education, training and employment promotes independence, confidence and long-term wellbeing.

Services delivering good practice can usually demonstrate access to psychosocial support and opportunities for peer connection, recognising these as important components of high-quality kidney care.

Young people and young adults living with kidney disease experience higher rates of psychological, social and practical challenges than their peers. These may affect confidence, education, employment, independence, identity and wider participation in everyday life.

Psychosocial wellbeing influences engagement with care, confidence, empowerment and the ability to participate meaningfully in shared decision-making.

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When psychosocial needs are not recognised or supported, young people are more likely to disengage from services, particularly at transition points, and may find it harder to sustain treatment decisions over time.

Services should take a supportive approach when young people miss appointments, recognising that this may reflect anxiety, practical barriers or unmet support needs.

Supporting psychosocial wellbeing therefore forms an important part of person-centred care and enables young people to participate more actively in decisions about their health and future care.

What good looks like in practice – psychosocial and youth support

Services can usually demonstrate that:

- psychosocial or youth support is available within or linked to the service
- young people are supported to understand their condition and treatment
- support is available to build confidence, empowerment, independence and self-advocacy
- opportunities exist for peer connection or group activities
- youth workers or psychosocial professionals act as a bridge between young people, families and clinical teams
- families can access support where this would help adjustment and shared decision-making

Why This Matters

Young people who feel supported and understood are more likely to attend appointments, engage with treatment decisions and sustain those decisions over time.

Peer connection and trusted non-clinical support can also reduce isolation, improve confidence and help young people develop independence as they move towards adult care.

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Youth Work, Psychosocial and Family-based Support

Youth workers and psychosocial professionals embedded within or linked to kidney services can:

- provide trusted, non-clinical support alongside medical care
- help young people make sense of information and treatment decisions
- support confidence, empowerment, self-advocacy and independence
- facilitate peer connection and group activities
- act as a bridge between young people, families and clinical teams

Where available, services may also consider access to **family-based or systemic support**, recognising that parents, carers and wider family members play an important role in adjustment, shared decision-making and long-term outcomes.

This may include family therapy, family support sessions or equivalent approaches delivered by appropriately trained professionals. Such support can help families navigate uncertainty, manage anxiety, support communication and adapt to changing roles as young people move towards greater independence.

Provision of family-based support should be **needs-led and proportionate**, and offered where possible but is not mandated.

Support may be delivered directly within healthcare services or through partnerships with charities, patient organisations and other third-sector providers. These organisations often play an important role in providing peer support, youth activities, information and family support for young people living with kidney disease.

Access to **free, NHS-funded or charity-supported provision** is encouraged where available, recognising that cost can otherwise be a barrier to engagement.

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Example – supporting education, training and employment

Young people living with kidney disease should be supported to achieve their goals in education, training and employment as they move towards adulthood.

Services may help schools, colleges, universities or workplaces understand a young person's condition and how it may affect participation in education, training or work.

This may include:

- brief conversations with education providers or employers
- **letters or written documentation supporting reasonable adjustments in education, training or employment**
- simple written information explaining the condition or treatment
- short information videos or digital resources that can be shared
- supporting young people to increasingly explain their condition and needs themselves as confidence develops

These approaches can improve understanding, support reasonable adjustments and help ensure young people are not disadvantaged in education, training or employment.

Supporting participation in education, training and employment also promotes independence, confidence and successful transition to adult life.

The UK Kidney Association Transition / Young Adult Specialist Interest Group has developed example resources that services may use or adapt, including **template letters to support conversations with schools, colleges, universities or employers**.

Services may wish to:

- use these example letters directly
- adapt them to reflect local services
- develop additional letters where helpful
- share examples of effective resources with the SIG to support wider learning across kidney services

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These resources aim to support practical conversations about education, training and employment and help young people advocate for themselves as they move towards adulthood.

Example information resources for schools and education providers:
[Link to follow]

Example resources – youth work, peer and family support

(Illustrative examples only)

Examples of psychosocial and peer support for young people and young adults with kidney disease include:

- **REACH** – national virtual renal youth-led groups and activities supporting young people with kidney disease to connect, build confidence and develop life skills alongside healthcare - Appendix 2
- **National Young Adult Kidney Group** – a national peer support network for young adults with kidney disease providing connection, shared experience and patient voice
  https://kidneycareuk.org/get-support/young-adult-kidney-group-yakg/
- Youth worker-led kidney groups embedded within hospital services
- Charity- or hospital-led young adult groups and peer support sessions
- Family-based or systemic support (for example family therapy), where available

These examples illustrate good practice. Delivery models will vary depending on local context, workforce and available resources and are not mandated.

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Peer Support for Young People and Families

Alongside youth work and psychosocial support, access to peer support can play an important role in helping young people and families feel less isolated and more confident navigating kidney care.

This may include:

- peer support groups for young people and young adults
- parent or carer peer support groups
- mixed formats delivered in person or virtually

Peer support can normalise experiences, reduce anxiety and support shared decision-making by allowing individuals to learn from others at a similar stage.

Examples include national and local young adult kidney groups, condition-specific peer networks and parent-led support forums.

Creative, Community and Social Prescribing Approaches

Some services may also support psychosocial wellbeing through creative or community-based approaches, particularly where these align with individual interests or needs.

Examples may include:

- art, music or creative therapies
- structured group activities
- referral to community or voluntary sector organisations via social prescribing

These approaches can support emotional expression, confidence and engagement, particularly for young people who may find traditional clinical conversations challenging.

Such support may be delivered through partnerships, social prescribing or third-sector provision depending on local availability.

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Example – lived experience

"Having someone outside the medical team made a huge difference. I could talk things through properly and not feel rushed or judged."
- Young person

"Support for us as parents really mattered. It helped us step back in the right way and support our child to make their own decisions."
- Parent /carer

"When psychosocial and youth support are in place, young people engage differently. Decisions stick, transitions are smoother, and outcomes are better."
- Kidney healthcare professional

These examples highlight the role of psychosocial, youth and family support in enabling successful shared decision-making and sustained engagement with care.

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Good Practice 14 - All Standards Apply to Young Adults, Including Those Newly Presenting to Adult Services

All the above principles concerning patient empowerment and shared decision-making should be implemented for all young people irrespective of whether they have been transitioned or present for the first time in adult services.

Why This Matters

Young people entering adult services may be at very different stages of understanding and independence. Providing structured support helps ensure that all young people, whether transferring from paediatric care or newly presenting to adult services, are supported to develop the knowledge, confidence and skills needed to manage their condition.

Preparation and shared decision-making continue within adult services for young people transferring from paediatric care and for those who present initially to adult services during adolescence or early adulthood. Adult services therefore play an important role in supporting young people to develop confidence, understanding and independence in managing their condition, particularly where structured preparation or transition support may not previously have occurred.

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Good Practice 15 - Measure for Improvement

Measurement supports reflection, learning and improvement rather than performance management.

This approach aligns with NHS England's non-mandatory quality indicators for transition and shared decision-making, which emphasise structured preparation, meaningful involvement and reflection on patient experience. An extract of the relevant indicators is provided in Appendix 3.

In the context of transition, patient empowerment and shared decision-making, measurement helps services understand whether meaningful conversations are taking place and whether young people feel listened to and involved in decisions about their care.

Teams should measure for improvement on a regular basis:

- preparedness for transition
- experience of shared decision-making
- engagement and continuity across the 16+ pathway
- access to psychosocial support

Measurement should be proportionate, repeatable and focused on experience, supporting shared learning rather than performance management.

Why This Matters

Measuring shared decision-making and patient experience helps services understand whether young people feel listened to, informed and involved in decisions about their care.

Combining structured measures with qualitative feedback helps services reflect on practice, improve care, and strengthen preparation, conversations, and shared decision-making over time.

Capturing feedback on whether young people felt involved also helps services evaluate and improve the quality of shared decision-making.

Used in this way, measurement becomes part of an iterative process of learning and improvement, helping services refine approaches and continually enhance the quality of care and patient experience.

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What good looks like in practice – measurement and reflection

Services can usually demonstrate that:

- approaches are in place to measure shared decision-making and patient experience
- structured measures are used proportionately to support reflection and improvement
- qualitative feedback from young people and families is sought and considered
- findings inform service learning and improvement over time

Examples of measures referenced nationally include:

- **SDM-Q9 / SDM-Q9+1**
- **CollaboRATE**
- **Decisional conflict measures**

Use of the self-assessment and improvement checklist supports structured reflection on current practice, identification of areas for development and shared learning over time. The checklist aligns with national quality indicators and is intended to support improvement rather than ranking or punitive use.

Example – lived experience

"Being asked how involved I felt showed me that my opinion actually mattered."
- Young person

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Implementation and Getting Started

Key Message for Services

Patient empowerment and shared decision-making require structure, visible resources and consistent use.

Services that can demonstrate how they:

- prepare patients
- support shared decision-making conversations
- document decisions clearly
- reflect and improve over time

are delivering high-quality kidney care in line with the **What Good Looks Like framework**.

Practical starting points for implementation

Services beginning implementation may wish to:

1. ensure a structured preparation framework is in place
2. make shared decision-making prompts visible in clinic areas
3. introduce decision-specific pathways (e.g. dialysis choices)
4. ensure access to psychosocial or youth support
5. introduce Meet the Team orientation resources
6. review communication practices such as patient-addressed letters
7. use the self-assessment checklist to identify improvement priorities

Implementation can begin with small practical steps and develop progressively.

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Governance, Co-Production and Transparency

This framework has been developed for consultation with young people, parents/carers and multidisciplinary professionals and should be viewed as a living document.

Co-production with patients, families and professionals has informed the language, priorities and practical focus of the framework.

Roles held by contributors across NHS services, professional bodies and charitable organisations are declared in the interests of transparency and good governance.

One of the Specialist Interest Group co-chairs also leads the Ready Steady Go Hello charity. This framework does not recommend or mandate the use of any specific programme or tool and is intended to remain outcomes-focused and tool-agnostic.

Alignment with National Guidance

The principles described in this document align with national guidance on patient experience, shared decision-making and transition, including NICE guidance on:

- babies, children and young people's experience of healthcare (NG204)
- shared decision-making (NG197)
- transition from children's to adults' services (NG43)
- patient experience in adult NHS services (CG138)

Together, these frameworks emphasise structured preparation, meaningful involvement of young people and continuity of person-centred care across the life course.

Summary

Good transition and shared decision-making start early, support young people as emerging adults, use the 16+ pathway to evidence decisions and enable early referral, prioritise psychosocial wellbeing, and rely on clear patient-centred communication and continuity across services.

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Detailed Good Practice to Guidance Mapping Table

Good Practice Standard	***What the Standard Covers***	***Implementation Guide Section(s)***	***What Those IG Sections Provide***
GP1 – Early Preparation	*Start at 11–12 or diagnosis*	***IG1*** *(bookmark: IG1),* ***IG2*** *(IG2.1 & IG2.2)*	*Framework for preparation; embedding early and repeated preparation*
GP2 – Embedded in Routine Care	*Transition is everyone's business*	***IG1*** *(IG1),* ***IG6*** *(IG6)*	*Consistency across paeds/adult/primary care; shared responsibility*
GP3 – Revisited Regularly	*Discussed early and over time*	***IG2.1*** *(IG2.1),* ***IG1*** *(IG1)*	*Structured, longitudinal conversations; visible progression in notes*
GP4 – Developmentally Appropriate Care	*Autonomy paced to readiness*	***IG1*** *(IG1),* ***IG3*** *(IG3)*	*Developmental approach; SDM supports autonomy*
GP5 – Shared Decision-Making	*Decisions made with patients*	***IG3*** *(IG3),* ***IG4*** *(IG4)*	*SDM in routine and complex choices; pathways for treatment decisions*
GP6 – Write to the Patient	*Patient-addressed, clear letters*	***IG3*** *(IG3),* ***IG6*** *(IG6)*	*Patient-addressed letters; reinforces understanding/ownership*
GP7 – Personalised 16+ Pathway	*Where adult care will sit; responsibility*	***IG2.1*** *(IG2.1),* ***IG2.2*** *(IG2.2)*	*16+ planning discussions; early referral; orientation*

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GP8 – Information About Adult Services	*Orientation & Meet the Team*	***IG2.2*** *(IG2.2)*	*Orientation resources; who's who; how adult clinic works*
GP9 – Joint Working	*Joint clinics/early engagement*	***IG2.2*** *(IG2.2),* ***IG6*** *(IG6)*	*Warm handovers; early introductions; joint MDTs*
GP10 – Planned Transfer	*Agreed, communicated transfer*	***IG2.1*** *(IG2.1),* ***IG6*** *(IG6)*	*Transfer timing; clarity of responsibility; shared documentation*
GP11 – Place-of-Care Policy (16–18)	*Clear local arrangements*	***IG2.2*** *(IG2.2)*	*Orientation pathways; clarity for ED/urgent presentations*
GP12 – DNAs = Unmet Need	*Supportive re-engagement*	***IG5*** *(IG5),* ***IG6*** *(IG6)*	*DNA follow-up; psychosocial check-ins; rapid rebooking*
GP13 – Psychosocial & Participation	*Psychosocial wellbeing + EET*	***IG5*** *(IG5)*	*Screening; youth/peer/psychology support; school/work templates*
GP14 – Apply to All Young Adults	*New to adult care included*	***IG6*** *(IG6)*	*Adult orientation; SDM continues; autonomy reinforced*
GP15 – Measurement for Improvement	*Preparedness, SDM, continuity, psychosocial access*	***IG7*** *(IG7)*	*Proportionate measures; MDT reflection; iterative improvement*

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Self-Assessment and Improvement Tool

What Good Looks Like: Transition, Shared Decision-Making and Psychosocial Care
(Reflection, learning and service-improvement tool).

How to Use this Tool

This tool supports reflection and shared learning across paediatric, adult and community services. It helps teams consider how consistently the principles described in *What Good Looks Like* are being delivered across transition, shared decision-making and psychosocial care.

It is designed to be used collaboratively- for example in MDT meetings, service reviews, quality-improvement discussions or network learning events.

This tool is not for judgement, performance management or ranking. It provides a structured way for teams to understand current practice, identify priority areas for improvement and support shared learning over time. Services may wish to revisit it periodically (for example annually) to demonstrate progress.

A digital version of this tool will be available in the Ready Steady Go Hello format once finalised.

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RAG Rating

🔴 **Red – Not yet in place (a priority area for improvement)**
🟡 **Amber – Partially in place or developing**
🟢 **Green – In place and working well**

The RAG rating reflects the current position rather than aspiration.
Red items often highlight areas where simple early changes may have high impact ("quick wins").

Self-Assessment & Improvement Checklist

For each item, select Red, Amber or Green and record any comments, examples or evidence.

What good practice looks like	🔴	🟡	🟢	Comments / Evidence
Preparing for transition				
Transition preparation begins from around 11–12 years or at diagnosis				
Preparation is gradual and revisited over time				
Young people are recognised and supported as emerging adults				
Shared decision-making				
Young people are actively involved in decisions about their care				
Options, risks and preferences are discussed openly				
Support is provided for understanding (including learning disabilities)				

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The 16+ pathway				
The future care pathway is clearly explained				
Decisions about future care location are discussed early				
Decisions are documented and referrals made where needed				
A clear 16–18 place-of-care policy is in place and understood by all relevant teams				
Young people aged 16–18 are consistently accepted by one responsible team and not bounced between paediatric and adult services				
Moving between services				
Joint paediatric–adult discussions or appointments occur where possible				
Transfer to adult services is planned and communicated clearly				
Communication				
Letters are written directly to the patient				
Language used in letters supports understanding				
Psychosocial care				
Psychosocial needs are routinely explored				
Young people know how to access appropriate support				

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Education, employment and participation				
Support is provided relating to education, training or employment where needed				
Adult services				
Shared decision-making continues within adult services				
Young people newly presenting to adult services receive developmentally appropriate support				
Engagement				
Missed appointments trigger supportive follow-up and re-engagement				
Learning and improvement				
Services review experience of transition and shared decision-making				

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Addendum: Alignment with Recent National Guidance

Following completion of this framework, NHS England published guidance on transition.

This strongly reinforces the approach set out here – particularly the focus on early preparation, personalised care, shared decision-making and a life-course model.

This framework goes further by providing the structure, tools and measurement needed to deliver these principles in practice – creating a clear route from policy to consistent, high-quality care across services and long-term conditions.

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Ready Steady Go Hello Charity gratefully acknowledges the young people, families, healthcare professionals, patient organisations and partner organisations whose experience, expertise and feedback informed the development of this framework.

We particularly acknowledge the support and collaboration of the UK Kidney Association Transition/Young Adults Specialist Interest Group throughout its development.

Together, we share a commitment to improving patient empowerment, shared decision-making, psychosocial care and transition across the life course.

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APPENDIX 1

Illustrative Example of a Clinic Letter Written Directly to a Young Person

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Illustrative Example of a Clinic Letter Written Directly to a Young Person

Dear Johnny

I was very impressed that you remembered about your kidneys and why you see me. I said that we think your reduced kidney function may in part be due to you needing heart surgery as a baby.

We chatted about the reasons for needing long-term follow-up. You said that you remembered some of the following discussion:

Any patient who has had kidney failure as a baby does need to be followed up with monitoring of their blood pressure to ensure that it does not get too high (**high blood pressure is called hypertension**), to make sure there is no **protein in the urine** (this is called **proteinuria**), and to keep an eye on kidney function.

We know that hypertension and proteinuria damage the kidneys and can cause a more rapid decline in kidney function. We also know that if you treat hypertension and proteinuria, this can help slow down the rate of decline in kidney function.

Hence the need for long-term gentle follow-up so that we can start treatment if needed and help protect your kidneys for the future.

Why this matters

This example demonstrates communication written directly to the young person, using plain English, explanation of medical terminology, positive and strengths-based language, and clear explanations of why monitoring and treatment are important. Such letters can support health literacy, patient empowerment, shared understanding and self-management.

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APPENDIX 2

REACH – national virtual renal youth-led groups and activities supporting young people with kidney disease to connect, build confidence and develop life skills alongside healthcare.

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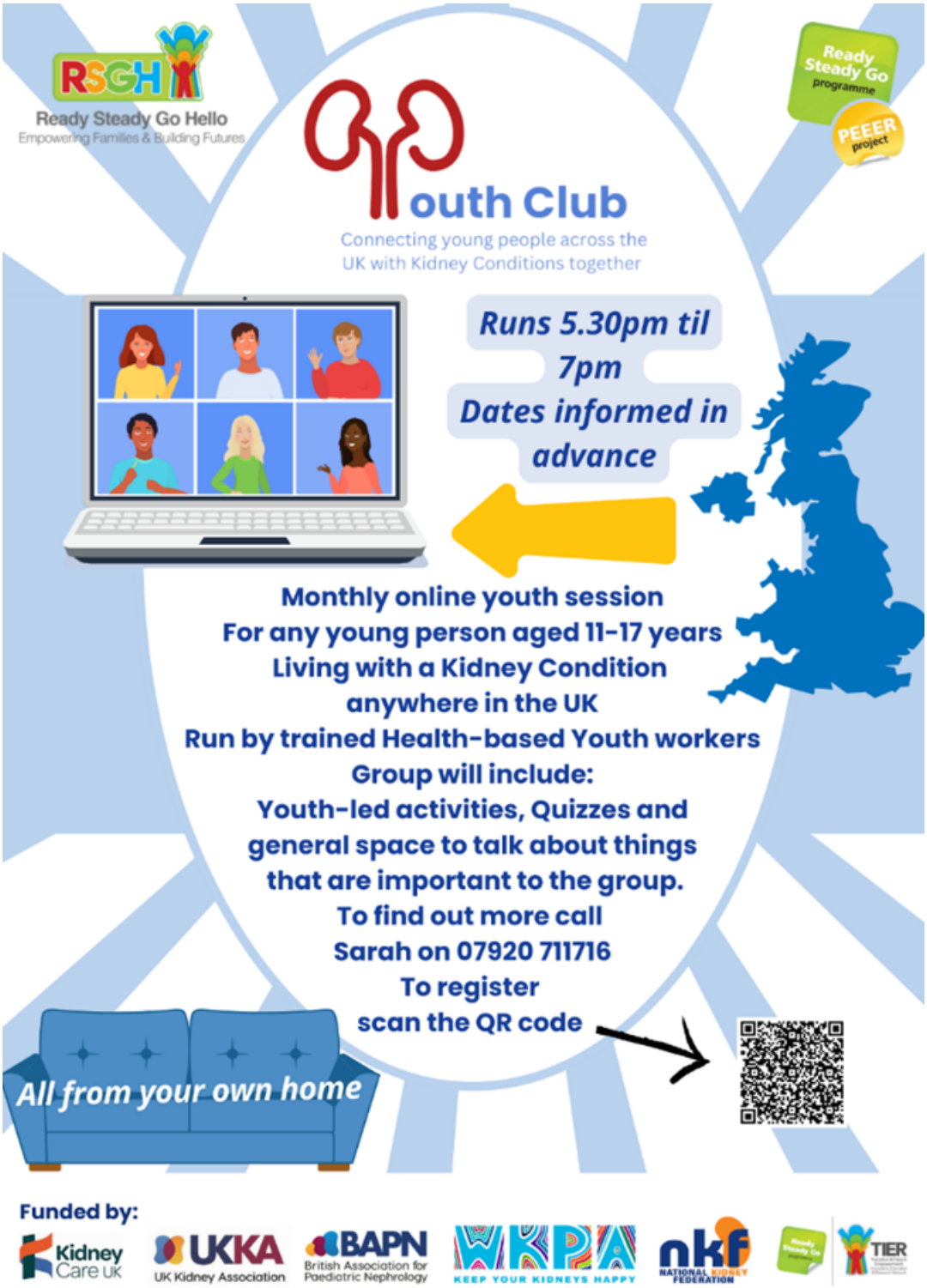

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APPENDIX 3

NHS England 2024/25 Quality Indicators Relating to Shared Decision-Making and Transition

Adapted from NHS England. Non-Mandatory List of Quality Indicators 2024/25: Guidance and Specifications.

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Table A. Achieving High-Quality Shared Decision-Making (SDM) Conversations in Specific Pathways

Component	Description
Quality Indicator	Achievement of high-quality shared decision-making (SDM) conversations in specific pathways.
Indicator Statement	The level of patient satisfaction with shared decision-making conversations, measured using internationally validated patient questionnaires at key decision points within pathways agreed with the commissioner.
Recommended Questionnaire	SDM-Q-9 is the questionnaire recommended by NHS England. The Making a decision together: SDM-Q9+1 is an Easy Read adaptation of the validated SDM-Q-9, designed to support accessibility and inclusivity for patients and families of all ages. Within the Ready Steady Go Hello and What Good Looks Like frameworks, it is the preferred questionnaire for measuring shared decision-making. CollaboRATE may also be used.
Purpose	To measure the quality of shared decision-making conversations and the extent to which patients feel involved in decisions about their care.
Numerator	Sum of scores for each question answered by each patient.

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Denominator	Number of patients on included pathways multiplied by the maximum score for each question.
Performance Requirement	Improvement in mean score between baseline and subsequent data collection, or maintenance of a score of 75% or above across the measurement periods.
Reporting Period	Quarterly reporting (Quarter 2 and Quarter 4).
Scope	Specialised acute services.
Relevance to What Good Looks Like (WGLG)	Supports routine measurement of patient empowerment and shared decision-making within kidney services and provides a nationally recognised mechanism for assessing patient experience.

Table B. Achieving High-Quality Transition to Adult Services

Component	Description
Quality Indicator	Achievement of high-quality transition to adult services.
Indicator Statement	For children and young people with long-term physical or mental health conditions, learning disability or autism, patient satisfaction with shared decision-making conversations relating to transition should be measured using an appropriate shared decision-making questionnaire.
Population	Children and young people aged 16 years and over with a long-term

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	condition transitioning to adult services.
Recommended Questionnaire	SDM-Q9 is the questionnaire recommended by NHS England. The Making a decision together: SDM-Q9+1 is an Easy Read adaptation of the validated SDM-Q9, designed to support accessibility and inclusivity for patients and families of all ages. Within the Ready Steady Go Hello and What Good Looks Like frameworks, it is the preferred questionnaire for measuring shared decision-making. CollaboRATE may also be used.
Purpose	To measure the quality of shared decision-making, involvement, preparation and patient experience before, during and after transition to adult services.
Numerator (Children's Services)	Total questionnaire score for all eligible young people following decisions relating to treatment and/or future care arrangements.
Alternative Measures Recognised by NHS England	Completion of the 'Go' component of the Ready Steady Go programme; completion of Step 8 ('Feeling confident to move into adult services') of the 10-Step Transition Pathway; or another agreed transition measure.
Adult Services Measures	Proportion of young adults who understand their role in shared decision-making and/or report opportunities to provide feedback on their transition experience.
Relevance to What Good Looks Like (WGLG)	Provides a practical and measurable approach to evaluating patient empowerment, shared decision-

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making and transition outcomes within routine kidney care and aligns with NHS England's quality framework.

Preferred Shared Decision-Making Measure

Within the Ready Steady Go Hello and What Good Looks Like frameworks, the The Making a decision together: SDM-Q9+1 is the preferred questionnaire for measuring shared decision-making because its accessible and inclusive format makes it suitable for patients and families of all ages.

Footnote: Adapted from NHS England. Non-Mandatory List of Quality Indicators 2024/25: Guidance and Specifications. NHS England retains copyright of the original guidance. Reproduced here for educational and implementation purposes within the UKKA What Good Looks Like framework.

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Document History

Version	Date	Description
1.0	April 2026	Initial release

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