Research Team

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Introduction

Following the development of the benchmarks for transition, sites were invited to pilot the benchmarks and provide feedback to help with the development of this guide to help with using the benchmarks in the practice setting. Between May and September 2015 meetings took place at three sites and were attended by approximately 125 health professionals.

The meetings followed the same format, beginning with a presentation about the development of the benchmarking document. Following this, in small groups, teams were asked to discuss the indicators of best practice listed for each of the benchmark factors and record the evidence they would use to demonstrate the achievement of each indicator. Small and large group discussions followed about the experience of using the benchmarks and feedback was collated from each site.

The aim of this guide is to give teams who wish to use the benchmarks some practical suggestions and tips on how to use them, based on our experience and that of those in the three pilot sites.

Why benchmark?

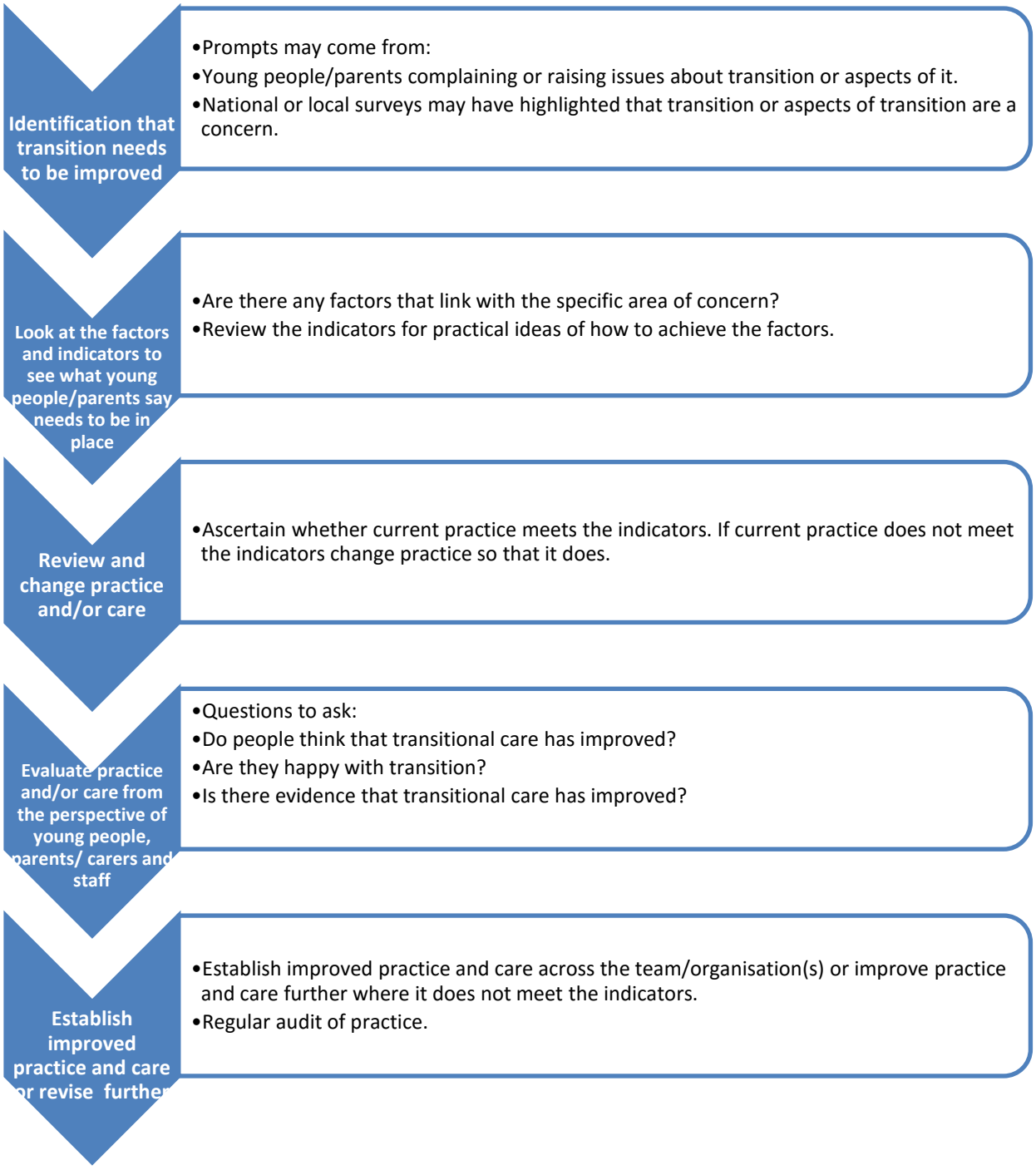
The benchmarks for transition have been developed in collaboration with young people, parents and health professionals and offers a 'practice guide' to support transitional care. Benchmarks provide a systematic approach to the assessment of practice. They can be used to show what services are doing well and where improvements need to be made.

The following comments were made by groups piloting the benchmarks for transition about their potential usefulness:

- The benchmarks provide a focus for discussion between child and adult teams.
- Allows teams to look at where they have been, where they are now and where they want to go as a service.
- Having the benchmarks allows the team to look at transition more formally.
- There were things that team members thought happened in their service but now realise they do not happen.
- There were elements of transition that teams thought they were doing well but after discussion realised they could improve.
- Services that are in their infancy can learn from what others are doing – the benchmarks facilitate these discussions and sharing.
- Good to have a document to show team members and engage them in thinking about transition.

Detailed guidance on the use of benchmarks is available in the 'How to use Essence of Care' document https://www.gov.uk/government/publications/essence-of-care-2010. The following 'quick start guide' has been adapted from this document[1].

Quick start guide for using the Benchmarks for Transition:



[1] Source: Department of Health (2010) How to Use Essence of Care 2010. TSO (The Stationery Office): Contains public sector information licensed under the Open Government Licence v2.0. http://www.nationalarchives.gov.uk/doc/open-government-licence/version/2/

Using the benchmarks for transition

Accompanying this document are the following:

1) A presentation that can be used to introduce the benchmarks to other team members.
2) The benchmarks for transition from child to adult health services.
3) A benchmarking document with space to record evidence.

Getting started

The benchmarks for transition consist of eight main factors and each of these factors contains a number of indicators of best practice. Some of the factors may not be relevant for every service and so it is not necessary to complete or achieve all of them. There may be additional factors that you wish to add in. You may decide to focus on just a few factors. Deciding which factors to focus on may come from young people/parents raising issues about that aspect of transition or from health professionals being particularly concerned about that area. The factors do not need to be completed in any particular order and are not presented in any order of importance.

Scoring

In the benchmarking document it is suggested that the benchmarking exercise starts by giving a score for that factor on a scale of 0 to 10 (0 = poor practice and 10 = best practice). This scoring acts as a rough guide to begin discussions around how team members think their service is doing for that factor. Feedback from piloting the benchmarks showed that when individuals completed the scores independently and then shared their responses with their team members, this generated useful discussion about differences in views of how the service was doing. If teams do not find the scoring useful it is not essential to use it, either use nothing or different scoring systems could be used if preferred. The number of indicators achieved does not equate to a particular score.

Listing evidence for the indicators of best practice

The indicators (or goals) of best practice all stem from suggestions made by young people, parents or professionals. Some of the indicators may not be relevant for every service and so it is not necessary to complete or achieve all of them.

Work through the indicators for the factor and list the evidence you would give to demonstrate the achievement of that indicator. Further information may need to be gathered to ascertain current practice/evidence, such as: reviewing documentation, observation, consultation with young people/parents. The types of evidence teams referred to during the pilot of the benchmarks were grouped into five main categories are presented

in Box 1 with some examples. Box 2 gives examples of responses listed for Factor 1 (Moving to manage a health condition as an adult).

Each factor has space at the end for the addition of local indicators that are relevant for that particular service.

Box 1: Types of evidence

Elements of the service that support transition:

- Joint MDTs
- Transition evening/day
- Visits to adult clinic/inpatient setting prior to transfer
- Adult nurse attends children's clinic/ children's nurse attends adult clinic
- Allocation of named nurse to contact about transition.

Information for young people/families:

- Leaflets
- Use of display boards/posters
- Written information given containing contact details the young person may need
- DVD about the adult service given
- Advice given in clinic
- Signposting to external/hospital/department websites to access: information on their condition/peer support/lifestyle.

Support for young people:

- Youth forum – encourage young people to join
- Information about events for young people with similar conditions provided
- Youth support worker on team
- Youth support worker leads peer support group.

Use of documentation/tools:

- Patient-held folders/transition record
- Information written in clinic letters
- Use of checklists/tools
- Child and adult teams use same electronic patient notes.

Training:

- Staff undertaking courses/ training on transition/ adolescent care including accessing e-learning courses
- Communication skills training.

Box 2: Examples of evidence recorded for Factor 1: Moving to manage a health condition as an adult

Indicators of best practice for factor 1	Evidence
a) Health professionals have good interpersonal and communication skills, good knowledge of the young person's condition and the ability to signpost appropriately.	Designated Clinical Nurse Specialist with role in transition. Attended courses and training about transition and young people. Patient feedback. Close working relationship between paediatric and adult teams.
b) Ensure the young person understands their health condition (including information about their treatment when they were younger and how it may affect them now and in the future).	Regular clinic visits where young person is seen by a consultant, nurse and physiotherapist. Discussions in clinic and with youth worker. Give young person opportunity to ask questions at each clinic. Document in patient transition record. Two way conversations with young people about their understanding, record it. Check verbally and written summary given. Report given to young person detailing health history. Use questionnaires to assess knowledge and gaps in knowledge.
c) Information on life as an adult with their health condition is given in an appropriate format.	Use of checklists. Given leaflets, dialogue with nurse and youth worker. Signposted to websites. Verbal information given. DVD on adult service is provided.
d) Information about their treatments and medications is given in an appropriate format.	Copies of clinic letters. Give leaflets. Discussed in clinic. Information sheets are given on specific drugs and information on how to access the pharmacist.
e) Information on how to order, collect prescriptions and book, rearrange and cancel appointments is given in an appropriate format.	Given information and leaflets about prescriptions and contact details. Contact numbers in patient held record. Done as part of our 'moving to high school' programme to increase independence. Keyworker/school nurse show where to go.
f) 'Lifestyle' advice is given (e.g. about healthy diet, alcohol, smoking, recreational drugs, exercise, sexual health, staying well).	Directed to websites. Give information leaflets. Display boards. Use of checklists. Information in patient held records.

g) Advice about work/future career or education is given.	Communication with team in clinic. Information in patient held records. Visits to workplace/college/university. Directed to charity website for information. Liaise with school and other professionals.
h) Advice about fertility and whether their condition can be passed on genetically is given, if appropriate.	Documented in medical notes. Give leaflets. Discussed and referred to genetics if necessary. We have developed a booklet given at around 14 years old.
i) The young person is helped to make decisions about the management of their condition and health at a pace appropriate to their needs.	See nurse and physio alone at suitable age. Young people set the agenda. Set a program individual to each young person and family. The young person is given choices.
j) The young person is helped to gain confidence when talking with health professionals without parent(s) being there.	Have part of consultation alone. Offer chance to be seen alone. All documentation is addressed to the young person. Young person is given the choice about whether parent is present.
k) Information about external support services and charities is offered.	Advocate use of charity website. Have information boards in clinic area. Youth support worker provides information. Involve social worker if any issues.
l) Information on where to go for further advice is given (including contact details for the medical team/consultant/Clinical Nurse Specialist/primary care).	In patient held record folder. Email contact details given. Team contact details given.
m) The young person is guided to make the most of peer support.	Young people signposted to family support websites. Can share contact details for a young adult with their condition who is happy to support young people. Youth forum. Give information about peer support groups. A youth worker helps with this. Social groups guided by youth support worker.

What next?

Use the benchmarking document to identify achievements and gaps in current practice. Develop a plan of what goals need to be met to improve practice; work out what needs to be done and how. This will involve looking at what the barriers to change are and how these could be overcome. Plans should be realistic and achievable. Sharing information with other teams and organisations can be useful to learn from each other about strategies to aid progress in achieving particular indicators.

Implement the plan and set dates for review. It is helpful to identify a named lead person to act as a driver to maintain progress. Reassess using the benchmarking document to see if there is evidence of improvements and highlight new areas for further improvement. An ongoing cycle of reassessment and further goal setting helps to continuously improve practice and care.

Further resources

These benchmarks should be used in conjunction with The Department of Health's quality criteria for young people friendly health services, 'You're Welcome', which sets out principles to help commissioners and service providers to improve the suitability of health services for young people https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services

Further information about the development of the benchmarks for transition:

- Project website: www.transitionstudy.co.uk
- Aldiss, S., Ellis, J., Cass, H., Pettigrew, T., Rose, L. & Gibson, F. (2015) Transition from child to adult care - 'it's not a one-off event': development of benchmarks to improve the experience, Journal of Pediatric Nursing, 30, 638-647.

Information about benchmarking:

- Department of Health (2010) How to Use Essence of Care 2010. TSO (The Stationery Office) https://www.gov.uk/government/publications/essence-of-care-2010
- Royal College of Nursing (2014) Understanding benchmarking. RCN Guidance for nursing staff working with children and young people https://www2.rcn.org.uk/__data/assets/pdf_file/0005/586985/003_144_web.pdf

Documents/guidance on transition:

- Care Quality Commission (2014) From the pond into the sea: Children's transition to adult health services http://www.cqc.org.uk/content/teenagers-complex-health-needs-lack-support-they-approach-adulthood
- National Institute for Health and Care Excellence (2016) Transition from children's to adults' services for young people using health or social care services https://www.nice.org.uk/guidance/ng43
- National Institute for Health and Care Excellence (2016) Baseline assessment form https://www.nice.org.uk/guidance/ng43/resources
- Supporting young people in their transition to adults' services: summary of NICE guidance *BMJ 2016;353:i2225.* http://www.bmj.com/content/353/bmj.i2225

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