

Helping Hand: Support and empowerment for people living with diabetes, their families and clinical teams travelling through transition from paediatric to adult healthcare services

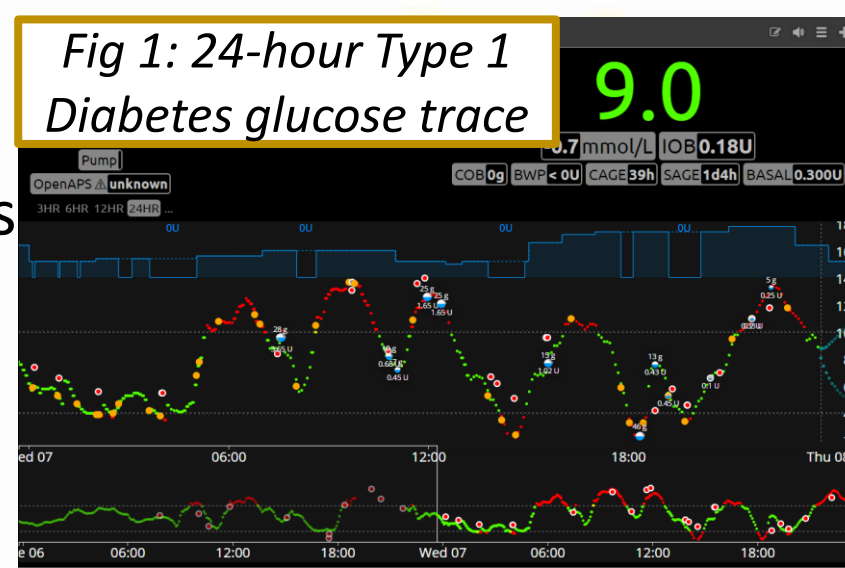
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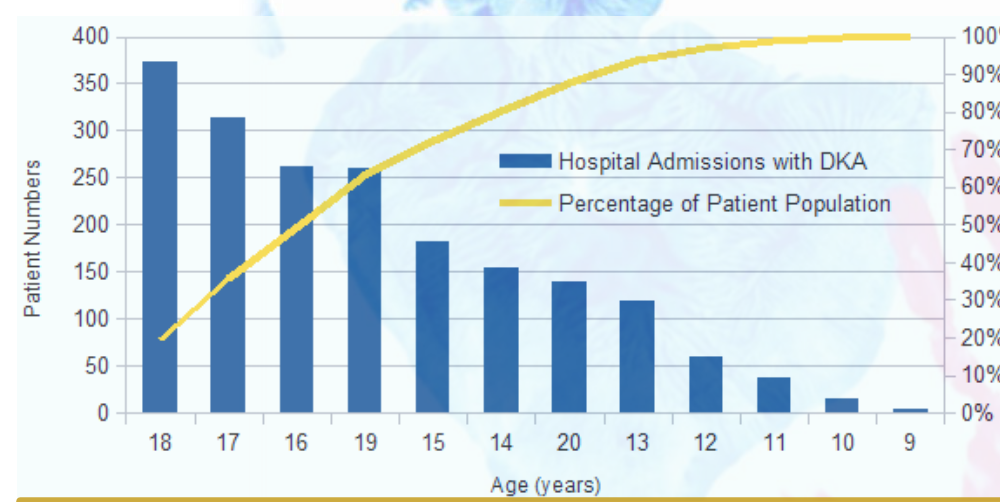
Aim: "How might we enable services to fit around each patient's individual needs, providing both clinical and non-clinical support throughout their transition journey?"

1. Why Type 1 Diabetes?

Insulin-dependent diabetes is hard & has significant acute & long-term risks. It's non-stop, with significant mental and cognitive burden [1] to keep on the glucose rollercoaster (Fig 1).



2. Why Transition?



Risk: Best Practice Tariff incentivises paediatrics to hang on to patients until their 19th birthday: locally, ~85% transfer at 17 or 18 years old. Local and National [2] audit data shows that some of the highest risks, such as Diabetes Ketoacidosis (DKA), Fig 2, occur during this time.

Timing: Diabetes transition is just one of many transitions encountered by patients and their families during this period.

These include both health and life events, such as puberty, sex and relationships, moving away from home, starting higher education and/or a full-time job and starting a family.

Lost to Follow Up: Patients are not engaging in services currently offered. Specialist service reviews are offered annually. But the period between attendance locally (for those under 25) is 2.5 years (range 0.2 – 7.6 years).

Almost 20% of patients are lost to follow up once transferred to adult service. "Who is looking after these patients?"

3. How? – Design Thinking

Design Thinking is a mix of empathy, identifying patient/healthcare professional's needs and problems and then iterating that concept collaboratively.

Stakeholders – patients, parents, healthcare professionals – aren't asked for feedback: they are *active participants* throughout.

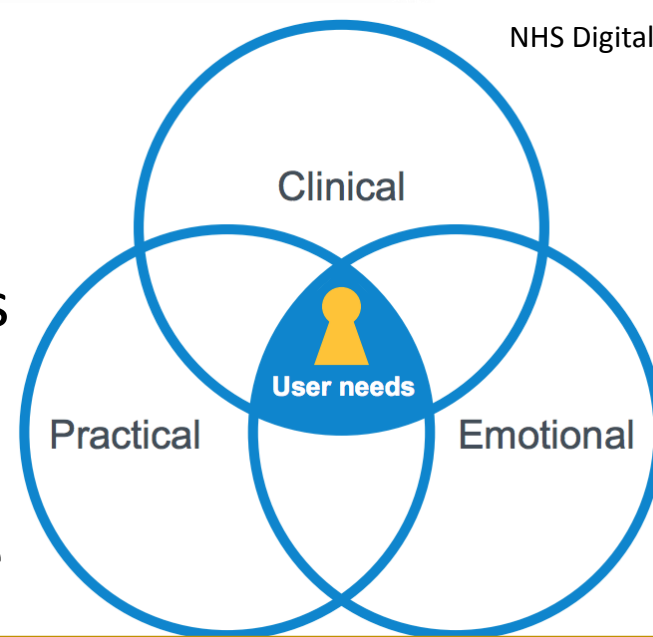


Fig 3: Human Centred Design aims to meet user needs

Human Centred Design & Quality Improvement

Both Human Centred Design (HCD) and Quality Improvement (QI) support change through rapid iterative cycles of creativity & testing. QI cycles follow **Plan – Do – Study – Act**.

HCD has **Observe – Ideation – Prototype – Test**

In HCD, *both* problems *and* potential solutions (the change being tested) are prototyped & tested (shown by Double Diamond [3]). HCD enables virtual "PDSA"-type cycles to be quickly evaluated.

QI is familiar to most NHS clinical staff. HCD is more approachable for patients and parents, engaging them in identifying the problem.

4. Which Problem to Solve?

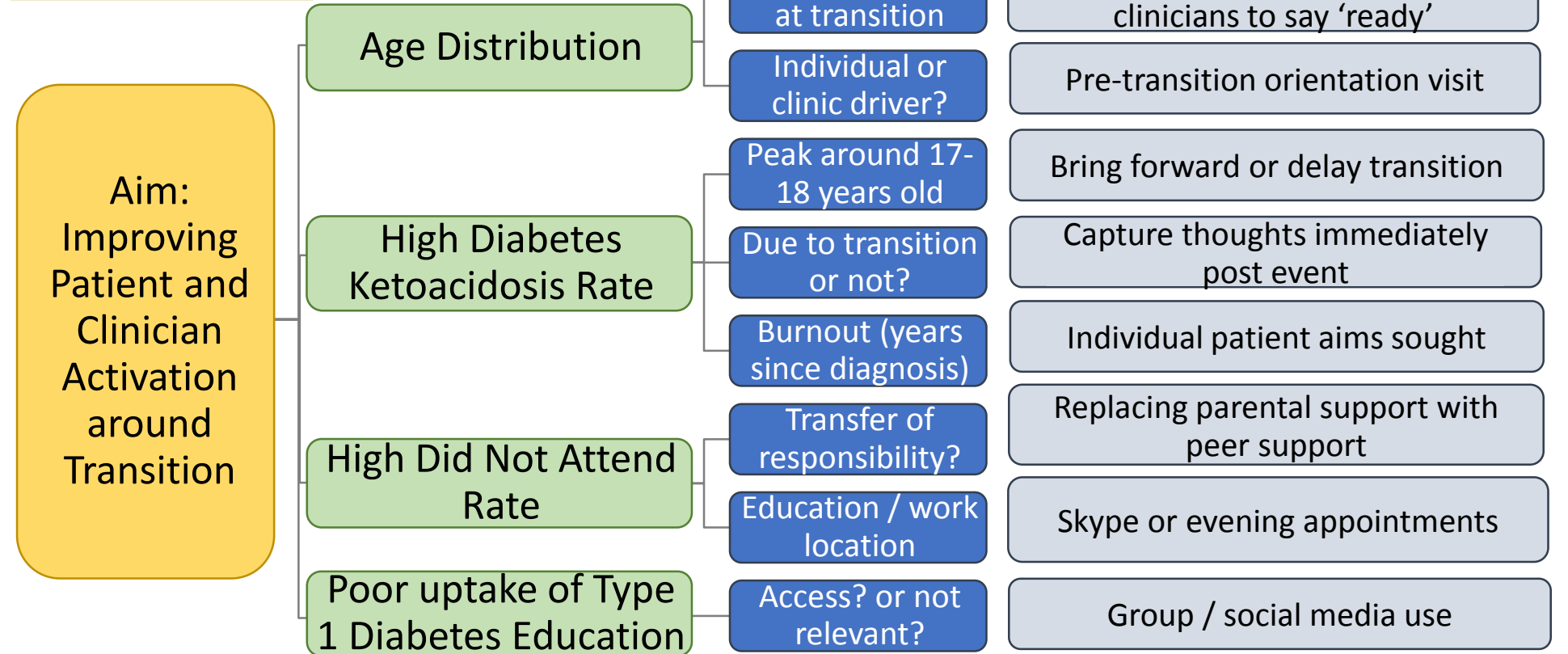
Traditional research tools fused with design workshops, initially with groups of five patients and also staff (nurses, diabetologists, administrators, youth worker) from paediatric & adult services.

Ideation and prioritisation involved three additional regional healthcare providers, commissioners and parents (Figs 4, 5, 6).

References

- [1] Diabetes Transition and Young Adult Service Specification and Guidance, NHS England, 2016
- [2] National Diabetes Transition Audit Report, NHS Digital, 2017
- [3] Eleven lessons: managing design in eleven global brands A study of the design process, Design Council, 2005

Fig 4: Initial Driver Diagram



5. Insights from patients, staff and families

Listening: Form a more complete clinical & social picture by *consistent engagement* with patients and their families and starting conversation between teams *earlier*.

Empowering: Give individual patients the *tools* early on so they can help to shape and take *ownership* of their future care.

Visibility: Ensure "*who-knows-what*" and "*who's doing what*" are visible across clinical teams, to patients and to their families.

These insights led to the prototype **Care Navigator** opportunity.

Fig 5: Three overlaid patient journey maps, with their emotional journeys (black lines)

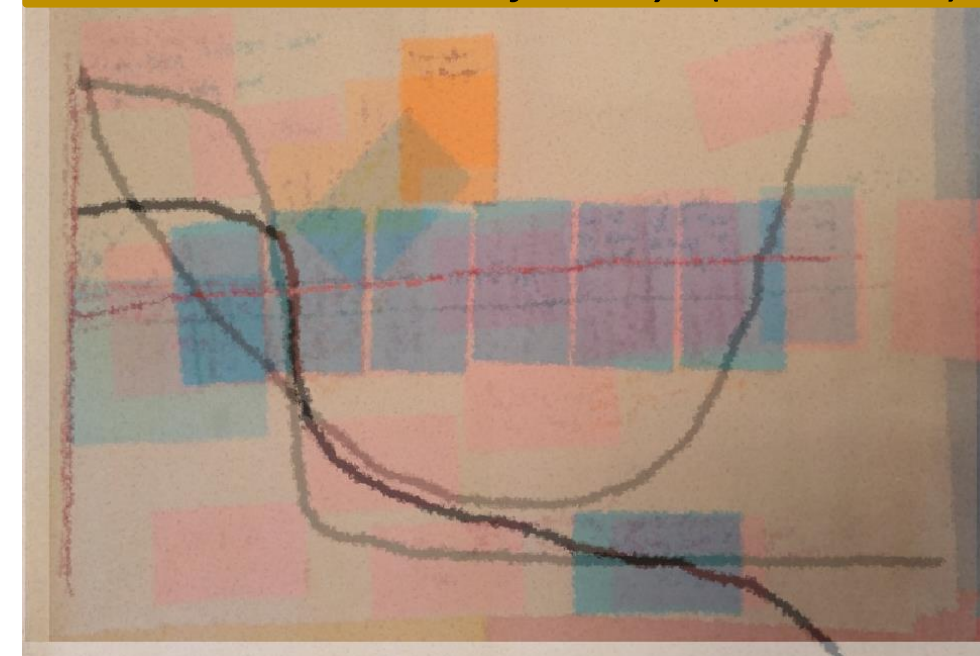
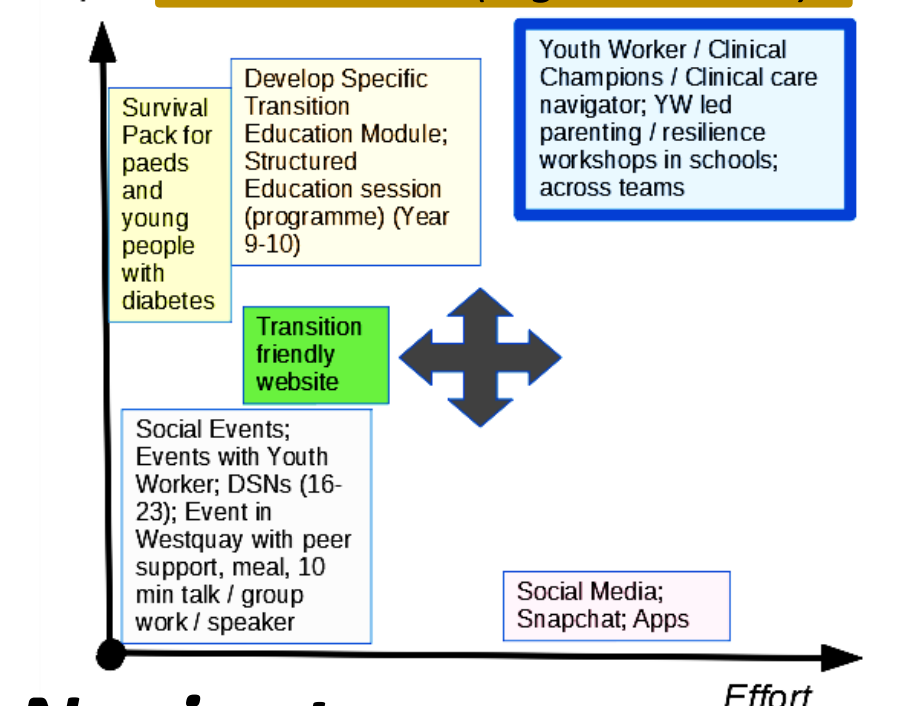


Fig 6: Prioritisation with wider stakeholders (digital Post-its)



6. Prototyping: The Care Navigator

Care Navigator Team (Fig 7) funded by Diabetes UK until end 2019, collating evidence for sustainable commissioning planned for 2020.

Iterating Navigator contacts using Behaviour Change wheel and PDSA.

New dynamic consent process puts patients in control of communication with parents and/or partner.

Capable of navigating primary and secondary care networks, sign-posting existing support, including peer support, for patients based on their individual needs. Enabling peer-led Type 1 Diabetes education and support groups.

Fig 7: Care Navigator Team



7. Lessons Learned and Reflections

It's not just about the diabetes; it's about living with diabetes.

Clinical teams & some patients are stretched & easily swamped – plan change accordingly, assuming existing resources will be full.

I'm not the expert, patients, parents & HCPs are. Support them by removing hierarchy, ensuring everyone has space for expression.

Facilitating change is an art as well as a science: don't be afraid to use both to engage, motivate, direct and drive change.

QI *plus* Design produced a methodology that's mobilised people.

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