ARTICULATING TRANSITIONS BETWEEN DIAGNOSIS AND INTERVENTION

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New diagnoses, new modes of life

- Changing diagnoses → new enactments of conditions → new interventions → new modes of living with a condition (for drs and patients)?
Story 1: early onset puberty

- Widespread concern about increasing rates of early onset puberty globally.
- Diagnosis = a highly contested field: how to diagnose, what to count as ‘early’ and/or ‘pathological’.
Technologies of diagnosis

**Orchidometer**

Used to measure testicle size and track sexual development in boys.

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Late Puberty | Adulthood

| 14 | 16 | 18 | 25 |

Testicle volume measured in mL

1 Inch
Old techniques but new (ethical) concerns → self assessment

New definitions → too much/too little intervention? (negotiations between clinicians and parents about how to live with this condition)
New diagnoses, new responsibilities

- Do new diagnostic technologies → new organisational practices, i.e. new responsibilities and roles?
Story 2: Preimplantation genetic diagnosis

- New technologies and knowledge $\rightarrow$ new experience of possible control/risk management
Liz: ...And it was interesting meeting the geneticists, who explained things ... in more detail and, and actually, you know, sort of made us aware of the pitfalls... They had all these em-, pictures of embryos to show us and because, I mean it’s taken me a long time to try and understand FISH, [laugh] because I just [more laughter] (yeah, us too....) [laughter] um, but, you know what was really good was to be shown examples of how something can be just hiding behind something else and those are things that you just, you know ... When I first sort of discovered it, I thought it would be so easy, so clear cut, `cause it seems so clear cut, and it was very good to have it explained to us that it’s not. And that um, some things are very difficult to detect.
Liz: But be-, I was on the one hand very lucky because I have just this amazing selection of embryos to choose from...

Celia: So they, and then they chose two.

Liz: They chose two. But it’s funny because afterwards my - I got a bit sort of paranoid and um, when we had our follow-up appointment with Professor Braude, I was, I was, I had loads of questions as you do, and there’s an anger there and, you know, but I, a) I had this problem with why the progesterone suppositories are not given earlier, and why do you wait till after the implantation, er, the transfer? And I, I couldn’t get my head round that. One of the biggest problems for me was how the... brain tells the body to start preparing if you haven’t been fertilised within the body and all that was explained to me.
Anne: We just couldn’t go through with another baby with SMA Type 1, we just couldn’t do it. We couldn’t do it to ourselves, but we couldn’t do it to another of our children, or our family. It would just be a definite no.
Anne: I mean if we was to find out that we was carriers of something else, and we were just going to produce a child that would inevitably be disabled, or whatever, we wouldn’t use PGD. You know, we see it as something that can… prevent children dying, basically, that’s why we’re using PGD.

Daniel: And it’s not even a case of um, I think with SMAs, it’s not even a case of ‘well they might die’. They will! There’s no question about it, they will!
Anne: I can understand it is a very grey area. Because obviously...we’ve used PGD because we didn’t want to have another child that was going to die within 12 months. But I mean, ... at what point do you draw the line? At a child that dies at 2 years, 5 years, 10 years, 20 years, 30 years? Where? ... What conditions are we going to allow PGD to be used for?... I don’t know where the line should be drawn.
New responsibilities

- New responsibilities for parents, patient groups, clinicians, scientists
- New roles connected to the above
- New demands on NHS – balancing needs, benefits, costs (contribution to ‘science’ as well as clinical outcomes)
Story 3: Pre-natal ultrasound screening

- Li-Wen Shih: PST in Taiwan
- Desire for a healthy baby and a health system that facilitates ‘shopping’ → high investment in PST
- New experiences of motherhood: anxiety and pleasure
- Familial responsibilities – folding of old and new
A image about dad and mom together bring 訪-孩 to a hospital

Tzi-Xing, 31 years old, first pregnancy, 15ws+ 1d, house wife, Taipei
Story 4: Pregnancy biosensors

- Intel Project (Roberts, Mackenzie, Mort) and Joann Wilkinson and Mette Kragh Furbo
- Technologies controlled by consumers; data shared online
- Possibility of continuous tracking → data overload (data of use to others?)
- Potential implications for dr/patient relations
DuoFertility

The ultimate aid to conception

See fertile days a week in advance!
Questions/ areas for research

- Folding of old and new – topological rather than linear approach to historical developments
- Iatrogenesis
- Significance of failure (vs hope)
- Changing relations between patients/consumers/clinicians/health bureaucracies/corporations
- Role of internet and related technologies of measurement, recording and statistical analysis
A reminder about ethical (‘who lives and dies and how’) questions

‘These questions cannot have simple, single or final answers. However, a serious commitment to refusing both the culture of no culture and the nature of no nature means these questions have to be asked, as a constitutive part of technoscientific practice’ (Haraway, 1997: 113).