



CRANE Database

Tel: 020 7869 6610

E: crane@rcseng.ac.uk

W: www.crane-database.org.uk

CRANE Database Meeting: Consultation on Database & Website Changes Summary of key points and suggestions

9 June 2015

1. Background

The CRANE Database and Website IT systems need to be updated. Therefore the CRANE project team compiled a specification to inform re-development and expansion of the capabilities of the CRANE database and website, and invited System Developers to review this specification and provide cost estimates for this work. This resulted in Crown Informatics Limited being appointed to work in collaboration with CRANE to complete this work.

Following the appointment of a system developer, the CRANE project team held a 'Consultation on Database & Website changes' meeting.

- **Aims & objectives:** This was to ensure our stakeholders could provide their views – in order to identify useful changes / features for the re-development of (1) the CRANE Database and (2) the CRANE Website for clinicians and patients & parents/carers.
- **Attendees:** The meeting was facilitated by Scott Deacon (SD) and was attended by a total of 28 people. 4 members of the CRANE project team (including SD), 18 representatives from across the regional cleft centres and specialties, 4 patient and parent/carer representatives (from CLAPA¹), and 2 members of the Crown Informatics Limited team².

This document provides a summary of the key points and suggestions raised at the consultation meeting.

2. Discussion of CRANE outputs over the next 5-10 years.

Top 4 messages/themes:

1. CRANE should look into expanding data collection beyond its current emphasis on 5 year old outcomes – to collect data at pre-school age, and for older children – into adulthood.
2. The CRANE Database system should help make it easier for cleft teams to enter that data required by allowing them to identify the gaps in their data.
3. In the long term, CRANE should seek to reduce duplication of effort for teams entering data into multiple systems – including hospital systems, CRANE and other local and national audits.
4. CRANE should ensure reports are more useful for patients and parents/carers – while considering the wider picture, and the fact that CRANE may possibly not be able to be 'all things to all people'.

¹ The Cleft Lip & Palate Association (CLAPA).

² A full list of attendees can be provided on request via crane@rcsenag.ac.uk.

The detail...

2.1. Clinical and patient reported outcomes that CRANE could collect + for which time points / age groups.

- Collect meaningful data, while keeping it simple.
- Audiology data.
- More outcomes before school-age. Including: Dental outcomes including the DEE at 1 ½-2 years, 3-4 years, and 5 years.
- More on appearance and speech – including speech outcomes at 15 years.
- More measures tracking development into teen years (12-13 years) and adulthood. CRANE' results appear to be too child-centred at this point. Monitor at what point these children move into adult services.
- Allow syndromic conditions to be better documented.
- More patient-centred outcomes – not enough of these. E.g. Psychological measures.
- Information on end-of-care.
- Attempt to address more of the top 12 research priorities identified by the James Lind Alliance. Including: Identifying the “types of psychological intervention (individual therapy, community or school based) and at what time (from diagnosis to adulthood) are most helpful for patients with a cleft of the lip and/or palate and their families” (Priority 1). E.g. 5 years, 8 years, 10 years and teenagers.

2.2. Additional (non-outcomes) data that CRANE could collect.

- Collect information on social care and community child health data. E.g. Health visitor's review at 2 years of age.
- More on the treatment pathway.
- Attempt to collect data (or do more work) to shed light on burden of care – how many appointments children/teenagers/young adults attend.

2.3. What CRANE could do to help ensure outcome / data collection.

- Allow for better downloads (or filters, or alerts) that can be used to complete data / provide clear lists of who is missing data (i.e. who has consented, fits criteria for audit, etc). Provide data coordinators with multiple flags highlighting missing data.
- Allow units to interrogate their data – e.g. list of consented cases with a cleft palate, etc (e.g. Cardiac Database).
- Allow better understanding of why data is missing. Plus allow better recording of DNA + other reasons data is missing.
- In the long term, seek to reduce demand on teams – considering the number of systems that require data entry (multiple data entry systems issue – local and national databases – dashboard/cleft collective/etc – duplication of effort – external benchmarking pressure – drain on resource).

2.4. Reporting / outputs from CRANE that could be useful to clinicians and patients/parents/carers.

- It would be useful to have more paediatrician involvement.
- Currently there is not enough information available – to patients – to inform decisions about treatments.

3. Features and ideas for the re-developed CRANE Database and Website.

Top 4 messages/themes:

1. It is very important to track transfers patients throughout their care – although some uncertainty remained as to how best to report on them (preference was to present them as a separate group/unit).
2. Ensure the new system can generate lists of consented patients (at the click of a button) – so teams know who's data to pursue (echoing point 2.3).
3. Visual reports (tables/figures) showing completeness of data would be very helpful – although this raised the issue of reports/figures/tables (within and outside the log-in) being based on 'raw' versus clean data.
4. It was also considered that it may be useful to record presence/absence of outcome data for non-consented cases. E.g. ticking a box if the patient has dmft data but without adding the full data.

The detail...

3.1. Management of transfers between centres / tracking patients.

- It is important to ensure visibility of 'old'/transferred cases. With a summary of registration details (where/when), surgeries (where/when), and outcomes collected at own centre before transferred to another.
- Alerts re transfers into your centre and out of your centre would be useful + a visible list of 'recent transfers'.
- It would be useful if CRANE could address tracking of patients in and out of private care (e.g. under some category of exclusion reason such as 'Externally Provided'), and transfers in and out of the country. Private care matter was thought to potentially become more relevant with time as commissioning groups increase rates of privatisation of services.
- Can CRANE provide guidance on how to reduce the rates of non-consent?
- What about allowing all units to view all data for all patients? There was some support for a multiple shared ownership model. Also, what about sharing patients' information with them?

3.2. Recording of data for non-consented cases, and other important groups of patients.

- It would be useful to be able to see e.g. at the top of the screen – a summary of all key patient details including 'status' = consented/excluded/etc.
- Flags to remind to follow up to seek consent would be helpful.
- Consent once children turn 18 and become adults – how will CRANE manage allowing them to 'opt out' of the registry?
- Also, if we start collecting adult outcomes, should consent be requested at the age of 16 – when many children are transferred to adult services?
- Prompts to help teams update postcodes would be useful (e.g. 6-monthly).
- Syndromic cases – felt to only be small numbers so maybe not work too much attention (conflicts with a point under 2.1)

3.3. How teams would like data feedback to them – instant reports / outputs.

- Reports and outputs need to be very easy to use – as data collection at units is also constrained by the skill set of administrators at each unit.

- More information on surgeries and outcomes of this was requested by patients. Cleft teams would be interested in how each teams repairs the palate and success of each method.
- CRANE potentially needs to consider who/what it's for – clinicians, commissioners, managers, patients? Is it possible to please and focus on all these groups (notion of not being able to be 'all things to all people').
- Patients and parents/carers are particularly interested in reports by cleft type – not just by region/unit.
- Reporting/summaries such as 'Understanding Bradford District Hospital: In your Pocket' (September 2013) was recommended – with key figures and the ability to click on each figure for context.
- Also look to a leaflet produced by GOSH of 'what parents want'.

4. **Next steps**

The team is to use this summary key points is to be (1) circulated to attendees, (2) made available on the CRANE website, and (3) used to inform the detailed specification of the new website and database.

We will involve attendees in user testing in the autumn/winter.

Teams are to provide further feedback via crane@rcseng.ac.uk.