

Implementation of an international quality improvement initiative for children with Inflammatory Bowel Disease (IBD) A UK site perspective of ImproveCareNow (ICN)

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Background

ICN is a large collaborative network based in the US, which collects data from children with IBD for quality improvement and patient centred research. ICN aims to improve and standardise the care of children diagnosed with IBD by creating a collaborative community of patients, families and health care providers.

ICN works by collating clinical information from the paediatric IBD population to a central registry, which allows clinicians to monitor the clinical status of patients along with overall performance between units. The network also facilitates sharing of best evidence and practice to improve outcome for patients.

There are currently 95 centres participating in ICN caring for over 27,000 children and young people with IBD. We are the 2nd UK site to join ICN, and the 1st in the UK using EPIC to collect and transfer data.

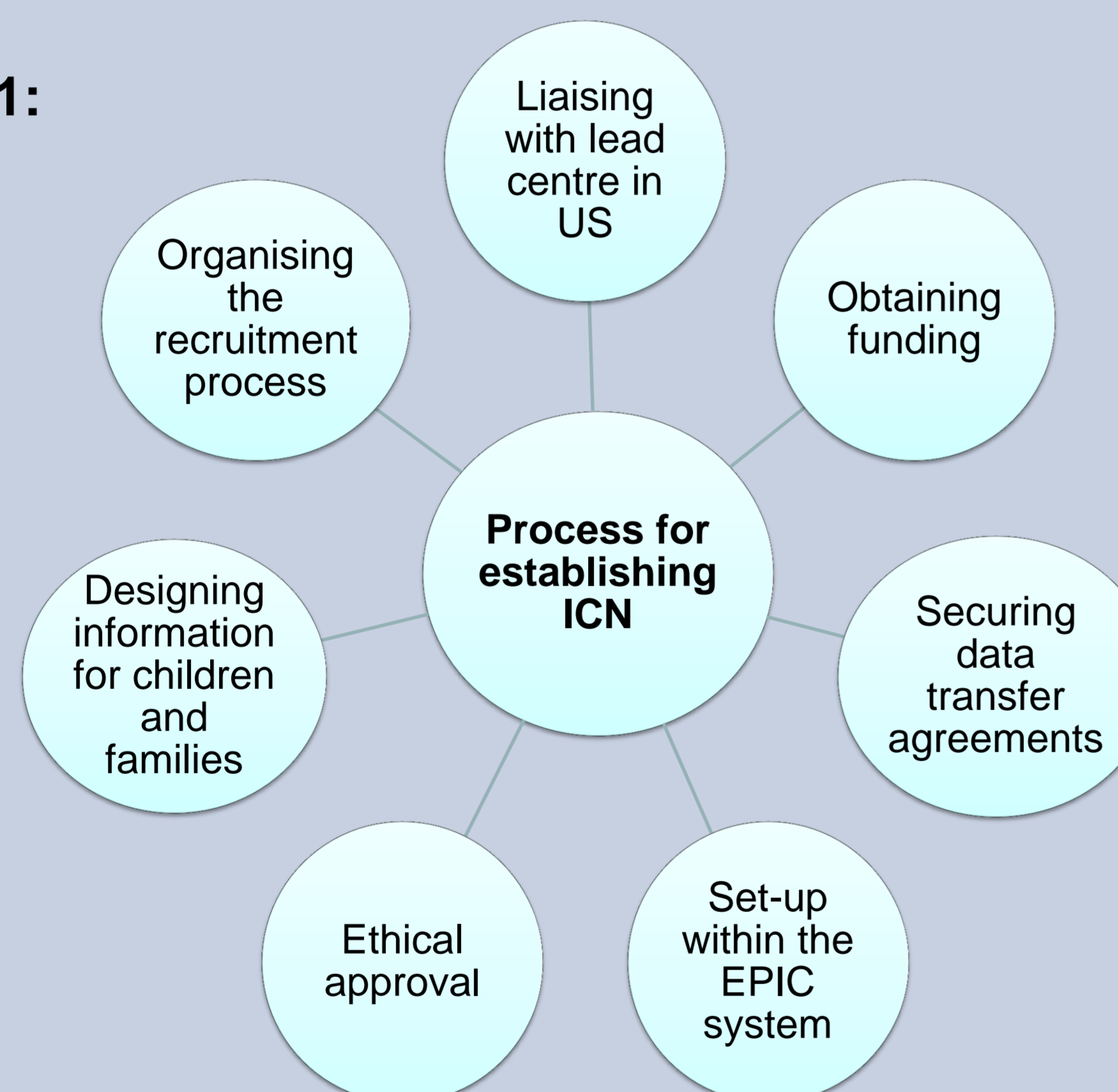
Aim

To present a report of the experiences, current progress and future challenges of a UK paediatric IBD team with joining ICN.

Key Obstacles

As a team we faced several challenges during the process of establishing ICN in a UK site. Figure 1 provides an overview of the main challenges we encountered.

Figure 1:

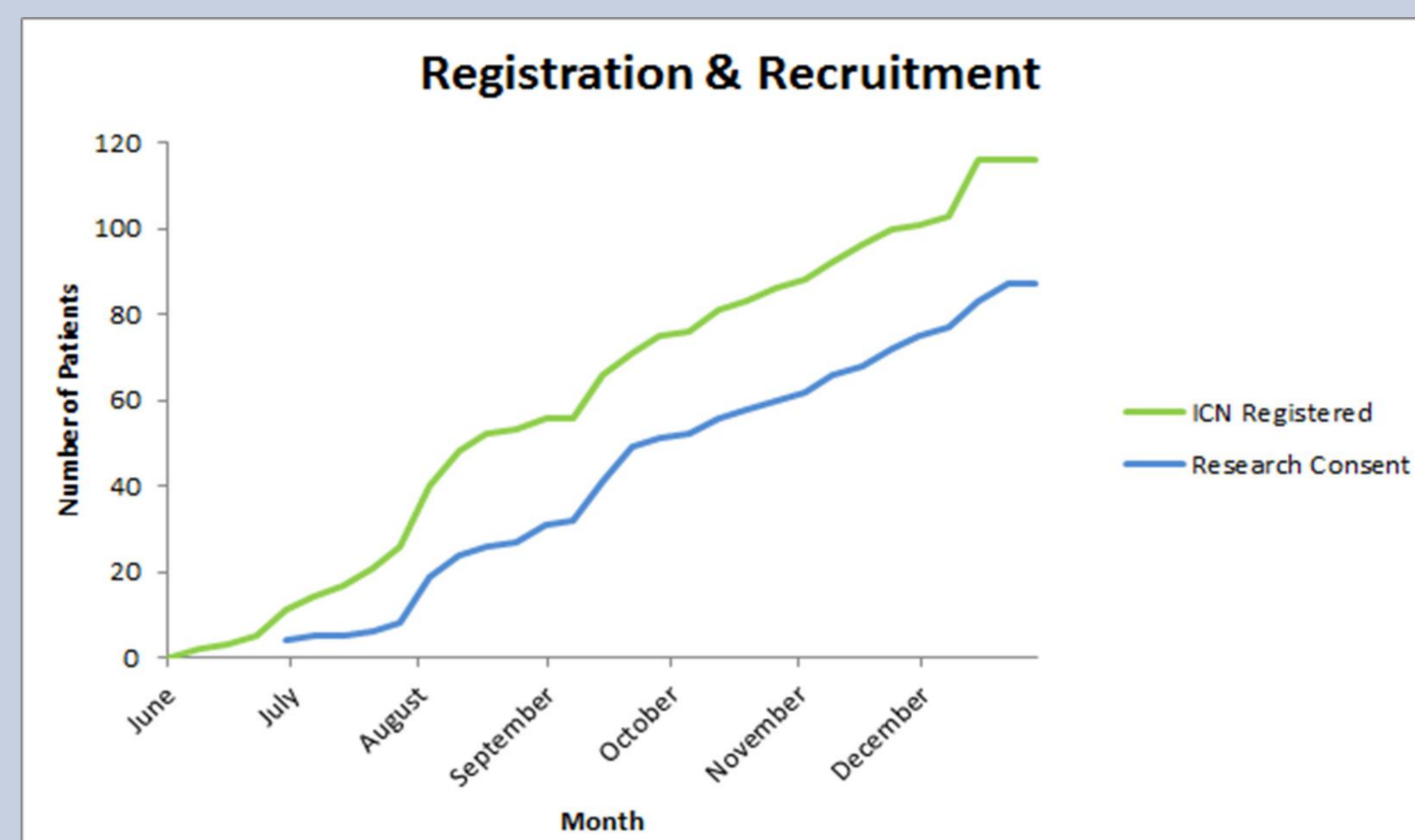


Current Recruitment

All children with a diagnosis of IBD were eligible for recruitment to ICN, with the exception of post-colectomy Ulcerative Colitis patients, and young people undergoing transition.

At the time of approval, 226 patients were eligible for registration for ICN. To date, 116 children have been registered (51%) and 90 (78%) of these have also given informed consent for their data to contribute towards future research. A cumulative graph of the recruitment rate is provided in Figure 2.

Figure 2:



Performance Measures

ICN sites are stratified according to the percentage of patients registered (<75% or 75% and above). In addition, they are grouped into Learning Labs with other centres who joined ICN at the same time. This allows benchmarking with sites at the appropriate time in their journey within ICN.

As the number of patients registered to ICN increases, the data generated will become more powerful. Reports generated from the ICN registry will allow us to concentrate on areas for improvement, and also focus discussions and resources on those patients who are flagged as moderate to high risk.

Table 1: Example of a Performance Report (cohort <75% registered)

	Sub-group	Measure	Cohort performance (% of patients)	CUH Performance (% of patients)
Clinical Measures	Clinical Remission	Clinical remission (PGA)	78	66
		Prednisolone free clinical remission	76	60
		Not taking prednisolone	95	89
	Adequate Nutrition and Growth	CD patients in clinical remission (PGA)	79	63
		UC patients in clinical remission (PGA)	77	73
		Satisfactory nutritional status	91	83
		At risk of nutritional failure	1	0
	Model Treatment	Satisfactory growth status	92	94
		At risk of growth failure	6	4
		TPMT measured when thiopurine started	63	100
		Dose of thiopurine at least recommended dose*	69	100

* Recommendations from the ImproveCareNow Model Care Guidelines

Future plans and Conclusions

We have started to embed formal pre-visit planning and population management in our weekly IBD workflow, using resources from across the ICN Exchange to modify processes in line with NHS systems.

ICN has great potential to transform the care, and hence clinical outcomes, of children with IBD. It also provides a unique dataset to perform future research studies, ultimately improving the lives of children and young people with IBD.

