

Antenatal and Newborn
Screening Programmes

Newborn Hearing Screening

Making IT Work for You

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Antenetal and Newborn Screening Programmes

Or Why Do Large IT Projects Usually Go Wrong???

- "Government IT projects have too often missed delivery dates, run over budget or failed to fulfil requirements." (2000)
- Why?
- Multiple stakeholders, stricter measures of success, policy uncertainty, poor project management, cultural misunderstandings, lack of communication, procurement bureaucracy, value for money vs highest bid, cultural gaps between IT and business management......

IT: Information Technology or Irritating Technology??



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A Brave New World? 21st Century IT for Healthcare

- National Programme for IT in England
- World's largest healthcare modernisation programme
- National summary care records and secure systems linking up other patient information across the country
- Official cost is £12.4 billion over 10 years
- Successes include NHS numbers at birth, PACS and a new national secure high bandwidth network
- Problems include concerns over confidentiality, scope creep, product delivery, spiralling costs and lack of stakeholder engagement

Antenatal and Newborn Screening Programmes

What do Users Want?

- Not to be sitting in front of computer more than necessary
- Not to have to re-enter data
- Not to be forced to do inappropriate actions by the IT system
- Not to have to change the way they've already been working
- To be involved and listened to

Antenetal and Newborn Screening Programmes

Newborn Hearing Screening in England

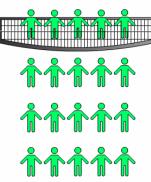
- Pilot started in 2001
- Rolled out national IT system (eSP) from early 2003
- All areas of England screening by March 2006
- NHSP Programme Centre based at the University of Manchester
- Over 2 million babies have been screened
- eSP system has evolved considerably based on lessons learned

Statistics for Financial Year 2006/07

- 524,975 records added to eSP
- 97.4% screens offered
- 93% screens completed
- For completed babies:
 - 93.7% clear responses with no follow up
 - 4.1% clear response targeted follow-up
 - 0.6% bilateral referral
 - 1.5% unilateral referral

Common Elements to Screening

1. Manage population through the process



2. Provide failsafe mechanisms

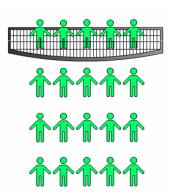


3. Monitor, evaluate & improve



Can IT Help?

- 1. Manage population through the process
 - Patient tracking with simple but flexible interface
 - Guide screeners through care pathway
 - Reminders





- Provide failsafe mechanisms
 - •Electronic birth notifications
 - •Screening manager reports to ensure no-one in target population missed





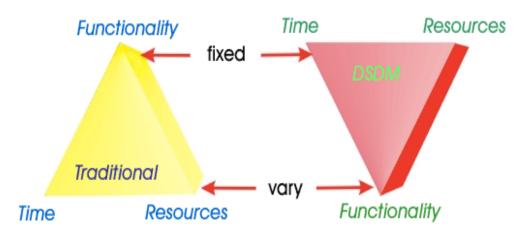
- 3. Monitor, evaluate & improve
 - •Enable consistent reporting
 - •Contribute to evidence base





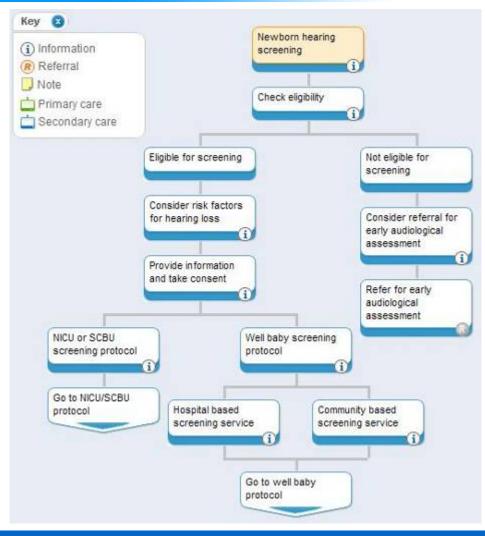
Meeting the IT Requirements

- Off the shelf product tailored to fit English programme
- Focus on baseline (minimum) requirements
- Involve user champions
- Prioritise requirements using MoSCoW criteria
 - Musts
 - Shoulds
 - Coulds
 - Won'ts





Clarifying the Care Pathway



A Difficult Balancing Act?

Users

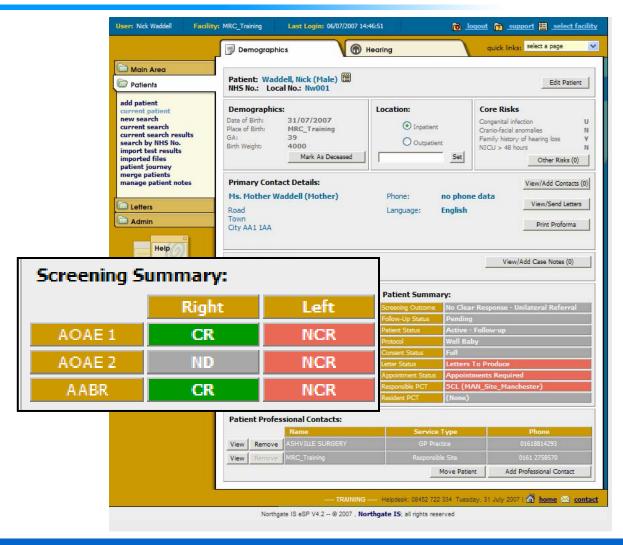
- Simple to use
- Quick to enter data
- Make decisions based on clinical experience
- Flexible



Central Programme

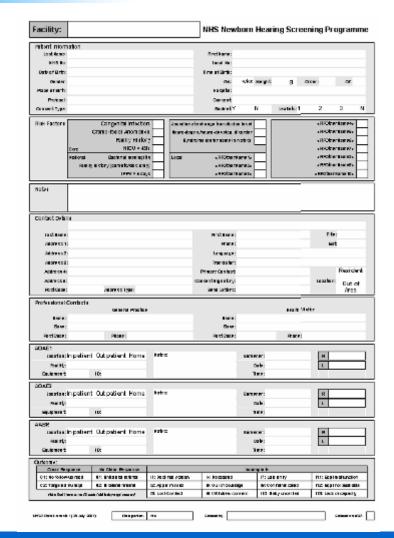
- Full audit trail
- Risk management
- Ensure good practice followed / mistakes minimised
- Consistent

Good Design



When IT is Not the Answer...

- Need to know when the best solution is not an IT one
- In England, the paper screening proforma is used to manage screening activity away from the computer
- Printed off for each baby after electronic birth notification received
- Used to record progress and update eSP when screening complete



Performance Management

- Performance management is...
 - ... the activity of tracking performance against targets and identifying opportunities for improvement in the future
- English Performance Management System
 - Data warehouse updated every night
 - Trends/metrics allow reporting on key performance indicators
 - Exception reporting to provide proactive warnings of concerns/issues
- Types of report
 - Quality Standards
 - National
 - Data quality
 - Ad hoc

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Turning Data into Knowledge

- Getting good quality data in (bits of information, eg. screening test results)
- Getting useful information out (organised data, eg. babies with high numbers of test results)
- Turning this information into practical knowledge (information imbued with intelligence, eg. how to minimise unnecessary repeat screenings to ensure no drop in screen sensitivity)

Why Definitions Matter

- Imagine someone asks you how many babies were screened in Manchester in July 2007...
- Does screened mean testing offered, started or completed?
- Does Manchester mean born in Manchester, resident in Manchester or having a doctor in Manchester?
- Does July mean born in July, screen started in July, screen completed in July (date of last test or date screening outcome set) or screen took place wholly in July?
- Plus, due to the possibility of outpatient appointments, screens may take some time to complete, so can only assess coverage accurately after several months (in England most reports run 3 months in arrears)

Quality Standards Report

QS	Objective	Std	#	%	#	%	#	%
	Total babies		asiss.		5631		4237	
	Total well bables		4347		5326		3935	
	Total NICU babies		e dese		305		302	
5	Screens offered	=9:96	4567	1000	5627	99.9	4237	100,0
8	Screens started	± 33%	4662	96.5	5444	96.7	4107	96.9
70	Screens completed by 4 weeks (hospital sites)	2 95%	5409	174,5	4776	84.8	3416	80.6
76	Screens completed by 5 weeks (community sites)		3486	76.5	4884	86.7	3553	83.5
7e	Screens completed by 3 months		5242	92.8	5351	95.0	4050	95.6
7d	Tests completed by 4 weeks	≥ 95%	3444	75.4	4808	85.4	3460	81.7
7e	Tests completed by 5 weeks		3516	77.0	4914	87.3	3582	84.5
7f	Tests completed by 3 months		4255	93.1	5369	95.3	4086	96.4
8	Screens declined	≤0.1%	0	0.0	0	0.0	1	0.0
	Referral rates from each stage of the screen							
9a	Well baby referrals from OAE 1 hospital	≤30%	1531	36.8	1628	31.5	1111	29.1
9b	Well baby referrals from OAE2 hospital	≤6%	768	18.4	1044	20.2	634	16.6

Information Governance

Defined by the NHS as...

...the way in which information is handled, particularly sensitive patient information, to ensure it is used legally, securely, efficiently and effectively to deliver the best possible care

- Poor information governance
 - Accidentally contacting parents of deceased babies
 - Equipment that does not require log on and allows users to delete data
- In England, working with equipment suppliers to improve information governance on their devices

Post-Screening

- Audiological assessment data is <u>vital</u>
 - Must be possible to identify true cases and show screen sensitivity
 - Provides evidence of success for securing ongoing funding
 - Informs successful early intervention
- New audiology module in eSP v4.2
 - Speeds up data entry
 - Based around English assessment standards
 - Allowed development of national register of children with Permanent Childhood Hearing Impairment (PCHI)

Lessons Learned (the hard way!)

- Keep things simple
- Find a supplier willing to work collaboratively and flexibly
- Sell the benefits to the stakeholders
- Minimise IT installation requirements
- Start the rollout process as early as possible
- Good project management
- Get electronic birth notifications as soon as possible
- Ongoing training and support
- Speed of fixing bugs and responding to user requests
- Involve audiologists from the outset

One Final Lesson: The Importance of Disaster Recovery



Antenetal and Newborn Screening Programmes

What Users Think

- "When eSP is working, it's so efficient, so good, that the minute it goes wrong, we're floored!"
- "Before we were always triple checking over and over again that we had screened babies and you were constantly worried."
- "I couldn't imagine the screening programme without eSP."
- "It would be awful if we didn't have it."
- "I think what's good about it is they listen to the users and the updates have taken on board what users wanted it to do."

NHSP Website



Thanks

- OZ Systems
- Prof Adrian Davis and NHSP Programme Centre
- Northgate Information Solutions
- Users of eSP

So can IT work for you?



* SMALL PRINT: WHEN IT'S CAREFULLY PLANNED, KEPT SIMPLE & BASED AROUND USERS