Putting research into practice: a pilot project to implement a new way for UK paediatric cardiac units to monitor their short-term surgical outcomes

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Need for monitoring

Regular ‘in-house’ monitoring of survival following surgery aids service improvement.

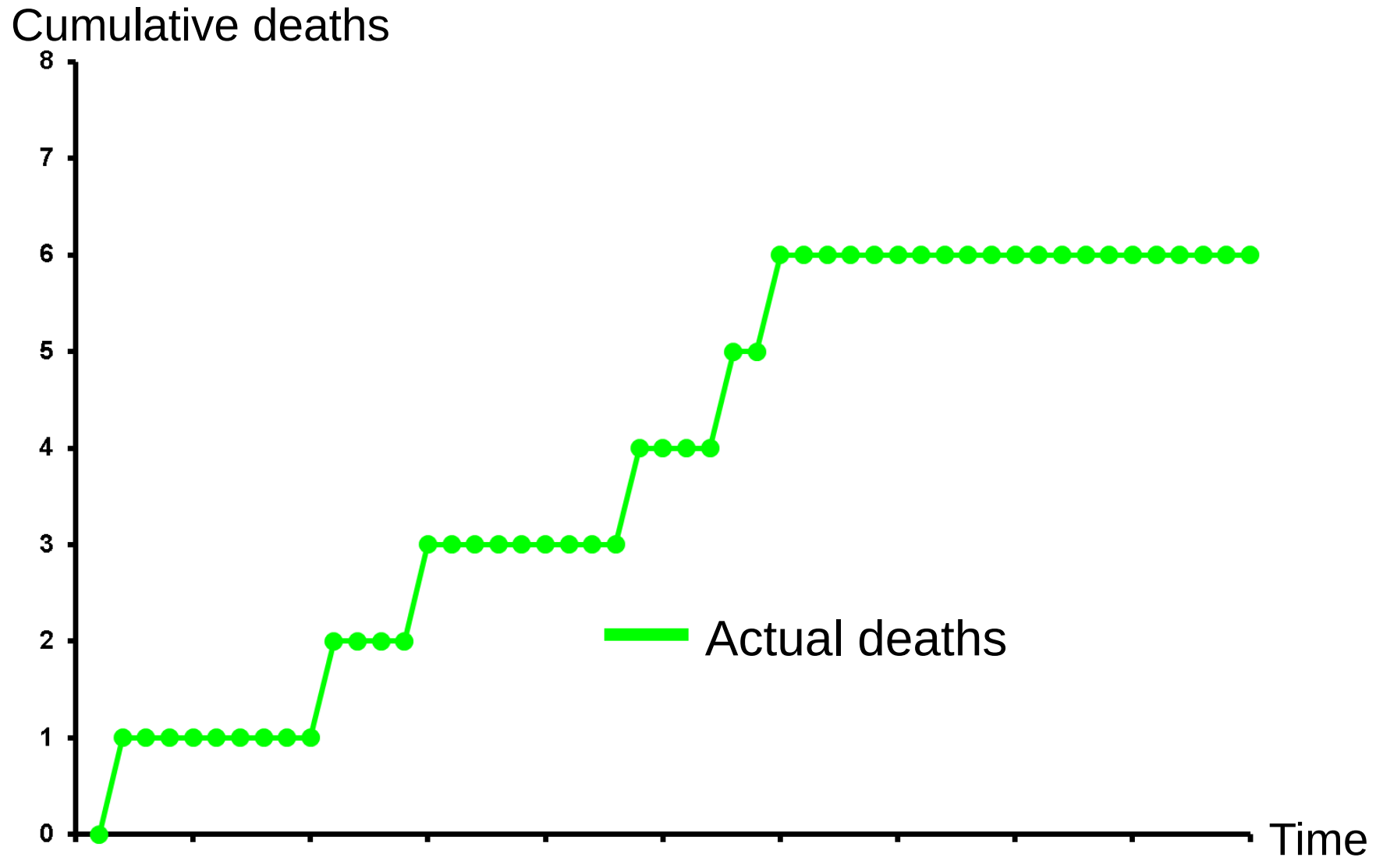
Highlighted as an unfulfilled need in paediatric cardiac services due to problem of adjusting for case mix.

We developed a risk model designed for such routine monitoring (Crowe et al. JTCVS 2012)

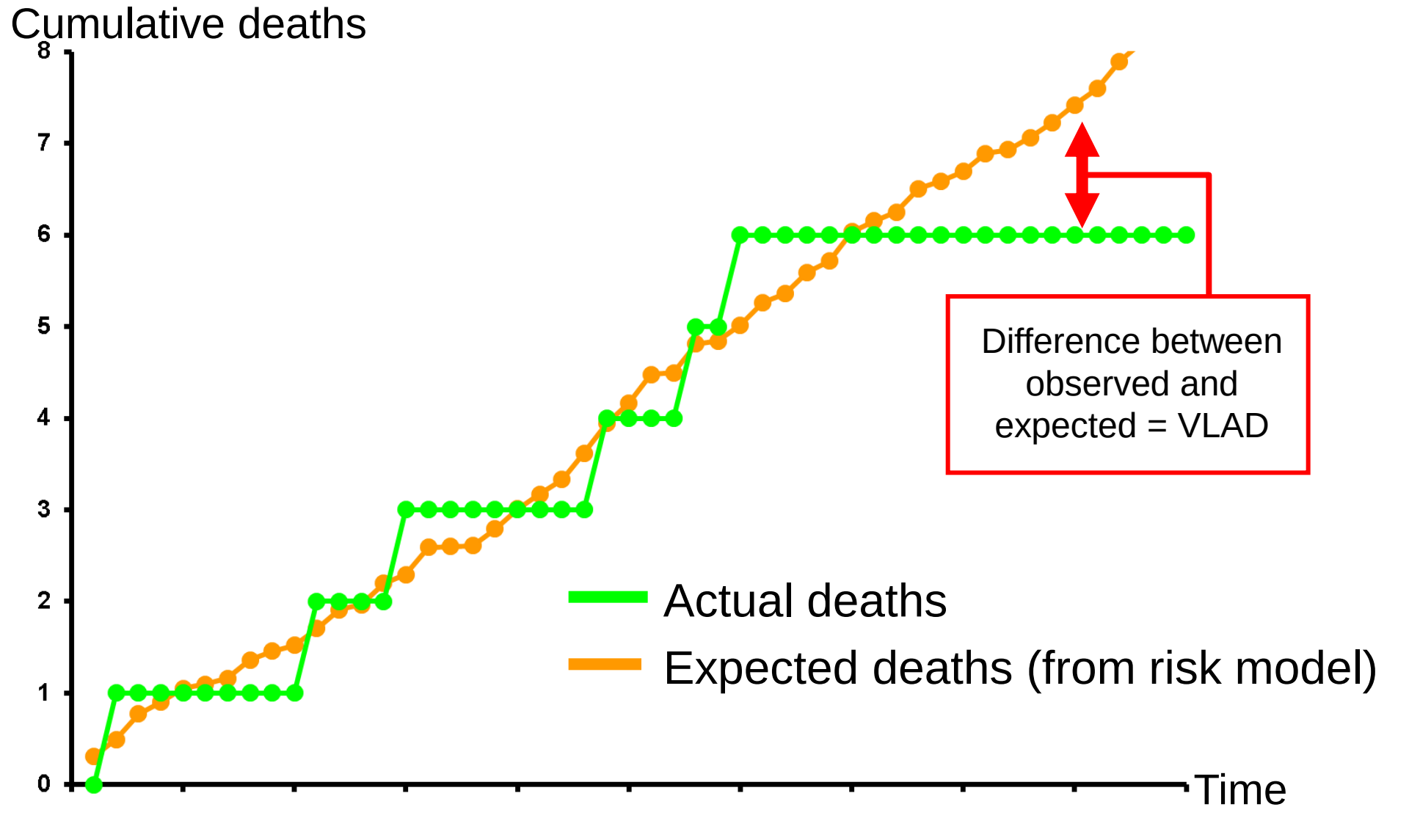
BUT – aim of this project was to get this into clinical use.

Three pilot units volunteered for the project…

Variable Life Adjusted Display (VLAD)

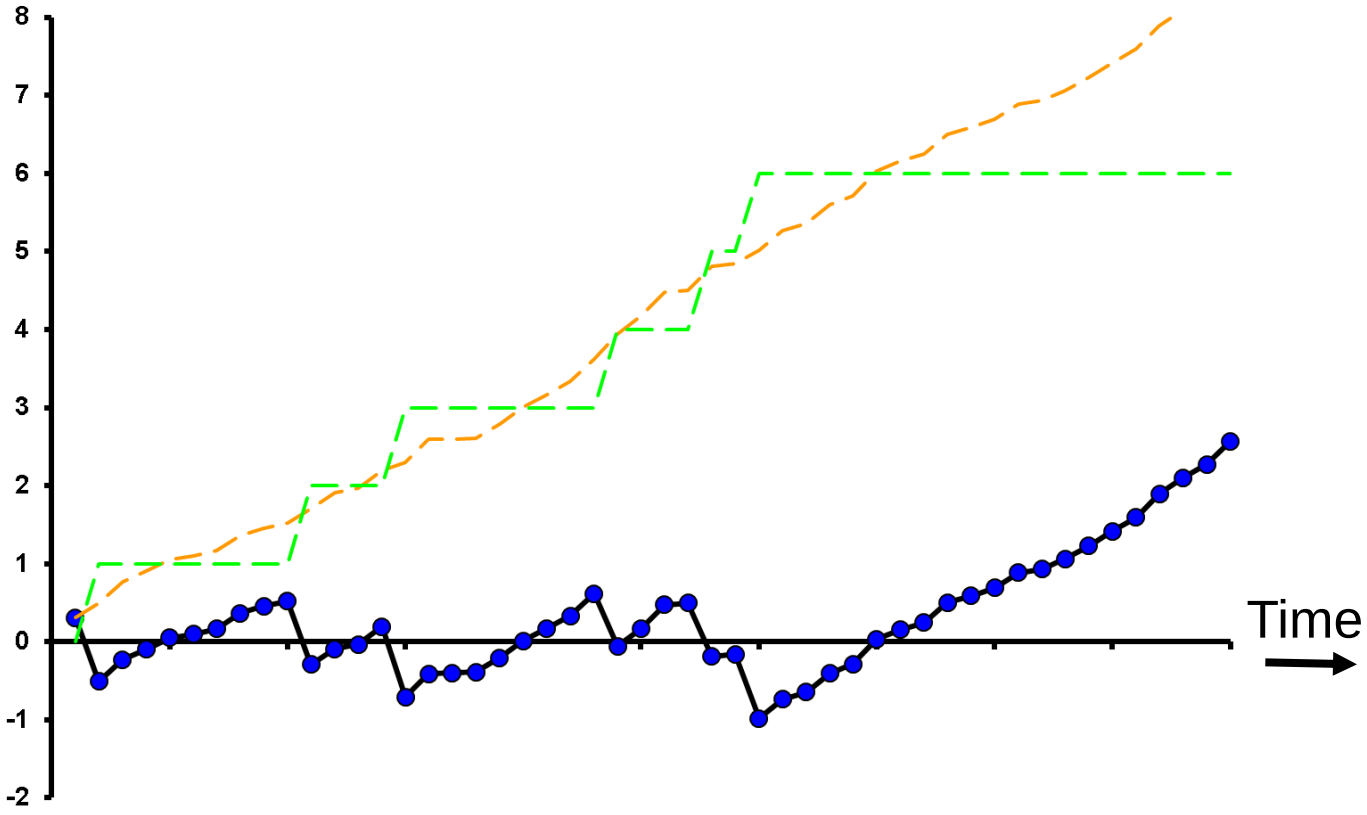


Variable Life Adjusted Display (VLAD)



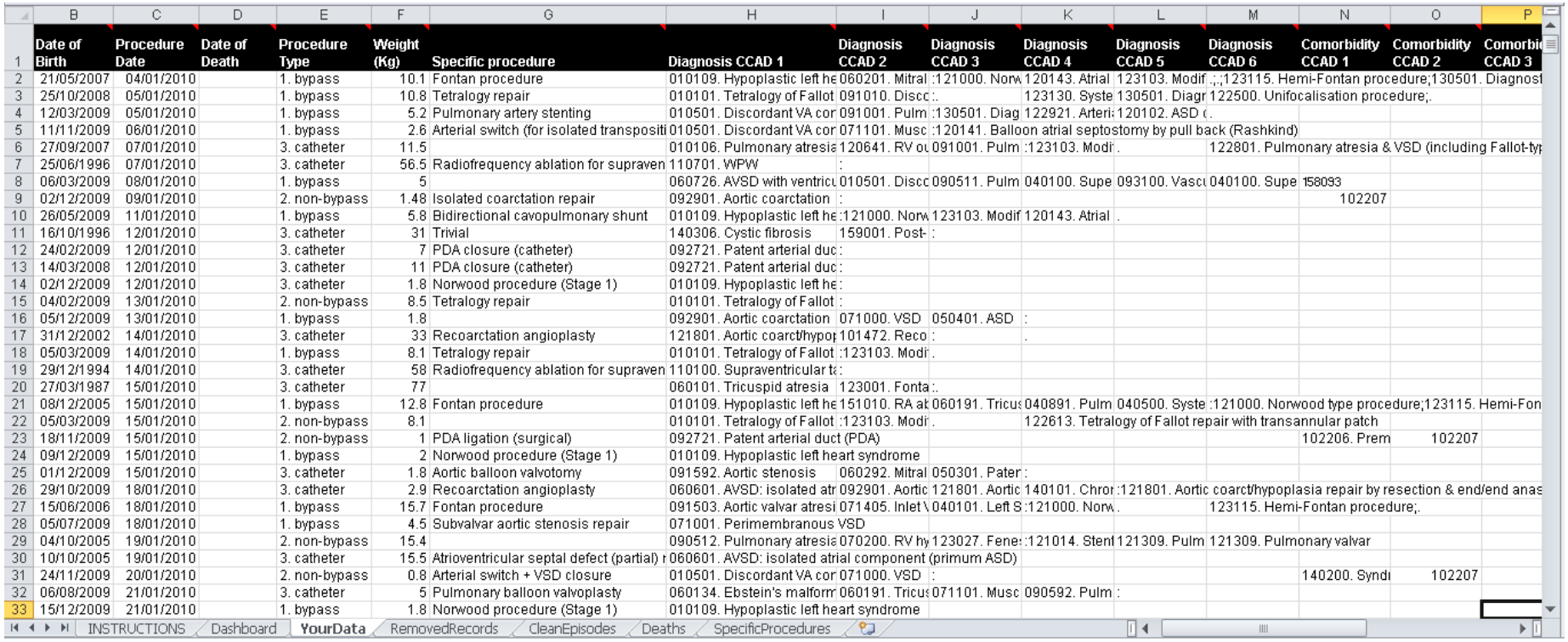
Variable Life Adjusted Display (VLAD)

Cumulative expected – actual deaths



We wanted to develop software that units could use in-house to generate regular VLAD charts using the new risk model

The final product

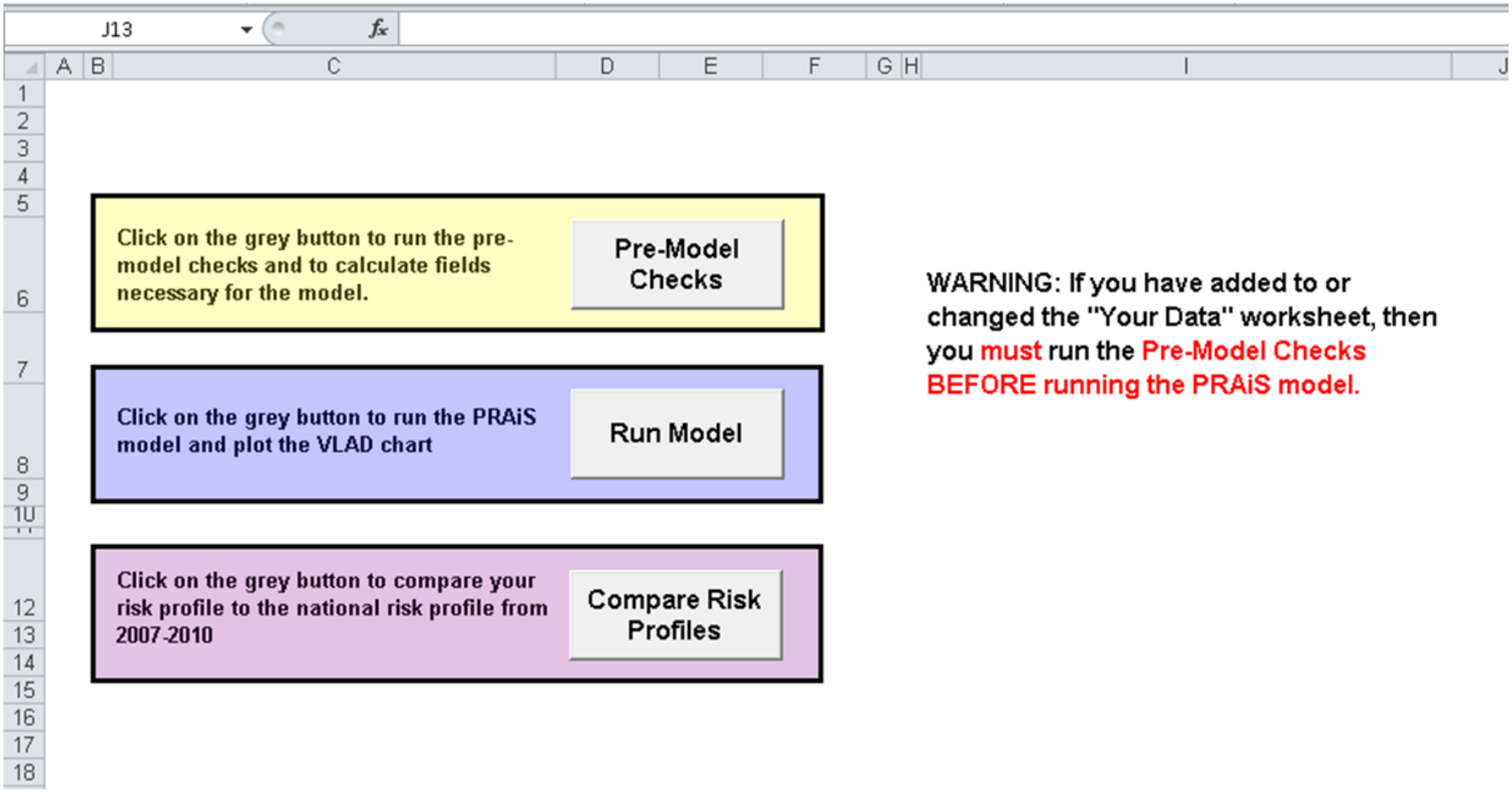


	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P
1	Date of Birth	Procedure Date	Date of Death	Procedure Type	Weight (Kg)	Specific procedure	Diagnosis CCAD 1	Diagnosis CCAD 2	Diagnosis CCAD 3	Diagnosis CCAD 4	Diagnosis CCAD 5	Diagnosis CCAD 6	Comorbidity CCAD 1	Comorbidity CCAD 2	Comorbidity CCAD 3
2	21/05/2007	04/01/2010		1. bypass	10.1	Fontan procedure	010109. Hypoplastic left he	060201. Mitral	:121000. Norw	120143. Atrial	123103. Modif	.;123115. Hemi-Fontan procedure;	130501. Diagnost		
3	25/10/2008	05/01/2010		1. bypass	10.8	Tetralogy repair	010101. Tetralogy of Fallot	091010. Disc	:.	123130. Syste	130501. Diagr	122500. Unifocalisation procedure;.			
4	12/03/2009	05/01/2010		1. bypass	5.2	Pulmonary artery stenting	010501. Discordant VA cor	091001. Pulm	:130501. Diag	122921. Arteri	120102. ASD (	.			
5	11/11/2009	06/01/2010		1. bypass	2.6	Arterial switch (for isolated transpositi	010501. Discordant VA cor	071101. Musc	:120141. Balloon atrial septostomy by pull back (Rashkind)						
6	27/09/2007	07/01/2010		3. catheter	11.5		010106. Pulmonary atresia	120641. RV ou	091001. Pulm	:123103. Modi	.	122801. Pulmonary atresia & VSD (including Fallot-typ			
7	25/06/1996	07/01/2010		3. catheter	56.5	Radiofrequency ablation for supraven	110701. WPW	:							
8	06/03/2009	08/01/2010		1. bypass	5		060726. AVSD with ventricu	010501. Disc	090511. Pulm	040100. Supe	093100. Vasc	040100. Supe	158093		
9	02/12/2009	09/01/2010		2. non-bypass	1.48	Isolated coarctation repair	092901. Aortic coarctation	:					102207		
10	26/05/2009	11/01/2010		1. bypass	5.8	Bidirectional cavopulmonary shunt	010109. Hypoplastic left he	:121000. Norw	123103. Modif	120143. Atrial	.				
11	16/10/1996	12/01/2010		3. catheter	31	Trivial	140306. Cystic fibrosis	159001. Post-	:						
12	24/02/2009	12/01/2010		3. catheter	7	PDA closure (catheter)	092721. Patent arterial duc	:							
13	14/03/2008	12/01/2010		3. catheter	11	PDA closure (catheter)	092721. Patent arterial duc	:							
14	02/12/2009	12/01/2010		3. catheter	1.8	Norwood procedure (Stage 1)	010109. Hypoplastic left he	:							
15	04/02/2009	13/01/2010		2. non-bypass	8.5	Tetralogy repair	010101. Tetralogy of Fallot	:							
16	05/12/2009	13/01/2010		1. bypass	1.8		092901. Aortic coarctation	071000. VSD	050401. ASD	:					
17	31/12/2002	14/01/2010		3. catheter	33	Recoarctation angioplasty	121801. Aortic coarct/hypo	101472. Reco	:	.					
18	05/03/2009	14/01/2010		1. bypass	8.1	Tetralogy repair	010101. Tetralogy of Fallot	:123103. Modi	.						
19	29/12/1994	14/01/2010		3. catheter	58	Radiofrequency ablation for supraven	110100. Supraventricular ta	:							
20	27/03/1987	15/01/2010		3. catheter	77		060101. Tricuspid atresia	123001. Fonta	:.						
21	08/12/2005	15/01/2010		1. bypass	12.8	Fontan procedure	010109. Hypoplastic left he	151010. RA at	060191. Tricus	040891. Pulm	040500. Syste	:121000. Norwood type procedure;	123115. Hemi-Fon		
22	05/03/2009	15/01/2010		2. non-bypass	8.1		010101. Tetralogy of Fallot	:123103. Modi	.	122613. Tetralogy of Fallot repair with transannular patch					
23	18/11/2009	15/01/2010		2. non-bypass	1	PDA ligation (surgical)	092721. Patent arterial duct (PDA)						102206. Prem	102207	
24	09/12/2009	15/01/2010		1. bypass	2	Norwood procedure (Stage 1)	010109. Hypoplastic left heart syndrome								
25	01/12/2009	15/01/2010		3. catheter	1.8	Aortic balloon valvotomy	091592. Aortic stenosis	060292. Mitral	050301. Pater	:					
26	29/10/2009	18/01/2010		3. catheter	2.9	Recoarctation angioplasty	060601. AVSD: isolated atr	092901. Aortic	121801. Aortic	140101. Chror	:121801. Aortic coarct/hypoplasia repair by resection & end/end anas				
27	15/06/2006	18/01/2010		1. bypass	15.7	Fontan procedure	091503. Aortic valvar atresi	071405. Inlet \	040101. Left S	:121000. Norw	.	123115. Hemi-Fontan procedure;.			
28	05/07/2009	18/01/2010		1. bypass	4.5	Subvalvar aortic stenosis repair	071001. Perimembranous VSD								
29	04/10/2005	19/01/2010		2. non-bypass	15.4		090512. Pulmonary atresia	070200. RV hy	123027. Fene	:121014. Stent	121309. Pulm	121309. Pulmonary valvar			
30	10/10/2005	19/01/2010		3. catheter	15.5	Atrioventricular septal defect (partial) r	060601. AVSD: isolated atrial component (primum ASD)								
31	24/11/2009	20/01/2010		2. non-bypass	0.8	Arterial switch + VSD closure	010501. Discordant VA cor	071000. VSD	:				140200. Syndi	102207	
32	06/08/2009	21/01/2010		3. catheter	5	Pulmonary balloon valvoplasty	060134. Ebstein's malform	060191. Tricus	071101. Musc	090592. Pulm	:				
33	15/12/2009	21/01/2010		1. bypass	1.8	Norwood procedure (Stage 1)	010109. Hypoplastic left heart syndrome								

INSTRUCTIONS | Dashboard | YourData | RemovedRecords | CleanEpisodes | Deaths | SpecificProcedures

*** Note: dates have been changed**

Dashboard


J13
Click on the grey button to run the pre-model checks and to calculate fields necessary for the model.
Pre-Model Checks
Click on the grey button to run the PRAiS model and plot the VLAD chart
Run Model
Click on the grey button to compare your risk profile to the national risk profile from 2007-2010
Compare Risk Profiles
WARNING: If you have added to or changed the "Your Data" worksheet, then you must run the Pre-Model Checks BEFORE running the PRAiS model.

Calculated factors and risk

	X	Y	AA	AF	AG	AI	AK	AR	AS	AT	AU
1	Caclulated 30-day Life Status	Calculated Age at Procedure (years)	Transformed Specific Procedure	Number surgical re-operations	Number catheter re-interventions	Number of re-interventions (caths+surgical)	Unique Episode ID	Diagnosis Group	Univentricular heart?	A non-Down's comorbidity?	Age band
2	0	15.18	Subvalvar aortic stenosis	0	0	0	E4_1	Medium Risk Diagnosis	1	0	Child
3	0	15.20	Pulmonary valve replacer	0	0	0	E5_1	Low Risk Diagnosis	0	0	Child
4	0	14.43	Aortic Valve Replacemen	0	0	0	E6_1	Low Risk Diagnosis	0	0	Child
5	0	15.19	Aortic Valve Replacemen	0	0	0	E8_1	Medium Risk Diagnosis	0	0	Child
6	0	14.96	Subvalvar aortic stenosis	0	0	0	E9_1	Medium Risk Diagnosis	0	0	Child
7	0	14.49	Pulmonary valve replacer	0	0	0	E10_1	Low Risk Diagnosis	0	0	Child
8	0	14.56	Subvalvar aortic stenosis	0	0	0	E14_1	Low Risk Diagnosis	0	0	Child
9	0	14.59	Pulmonary valve replacer	0	0	0	E15_1	Medium Risk Diagnosis	0	0	Child
10	0	12.80	VSD Repair	0	0	0	E18_1	Low Risk Diagnosis	0	0	Child
11	0	13.03	No specific procedure	0	0	0	E20_1	Medium Risk Diagnosis	0	0	Child
12	0	12.71	No specific procedure	0	0	0	E23_1	Low Risk Diagnosis	0	0	Child
13	0	12.48	Fontan procedure	0	0	0	E25_1	Low Risk Diagnosis	1	0	Child
14	0	11.59	Bidirectional cavopulmon	0	0	0	E29_1	Medium Risk Diagnosis	0	0	Child
15	0	12.54	No specific procedure	0	0	0	E31_1	Low Risk Diagnosis	0	0	Child
16	0	10.50	Pulmonary valve replacer	0	0	0	E34_1	Medium Risk Diagnosis	0	1	Child
17	1	8.88	Pulmonary valve replacer	0	0	0	E42_1	Medium Risk Diagnosis	0	1	Child
18	0	7.93	Aortic Valve Replacemen	0	0	0	E45_1	Medium Risk Diagnosis	0	1	Child
19	0	7.50	Subvalvar aortic stenosis	0	1	1	E46_1	High Risk Diagnosis	0	0	Child
20	0	6.97	Subvalvar aortic stenosis	0	0	0	E47_1	Medium Risk Diagnosis	0	0	Child
21	0	6.37	ASD repair	0	0	0	E48_1	Low Risk Diagnosis	0	0	Child
22	0	7.08	Fontan procedure	0	0	0	E50_1	Medium Risk Diagnosis	1	0	Child
23	0	5.30	Fontan procedure	0	0	0	E51_1	Medium Risk Diagnosis	1	0	Child
24	0	5.40	Bidirectional cavopulmon	0	0	0	E53_1	Medium Risk Diagnosis	1	0	Child
25	0	5.23	No specific procedure	0	0	0	E54_1	Medium Risk Diagnosis	0	0	Child
26	0	5.71	Bidirectional cavopulmon	0	0	0	E55_1	Medium Risk Diagnosis	1	0	Child
27	0	5.56	Fontan procedure	0	0	0	E56_1	High Risk Diagnosis	1	0	Child
28	0	4.01	Fontan procedure	0	0	0	E58_1	High Risk Diagnosis	1	0	Child

INSTRUCTIONS | Dashboard | YourData | RemovedRecords | CleanEpisodes | Deaths | SpecificProcedures

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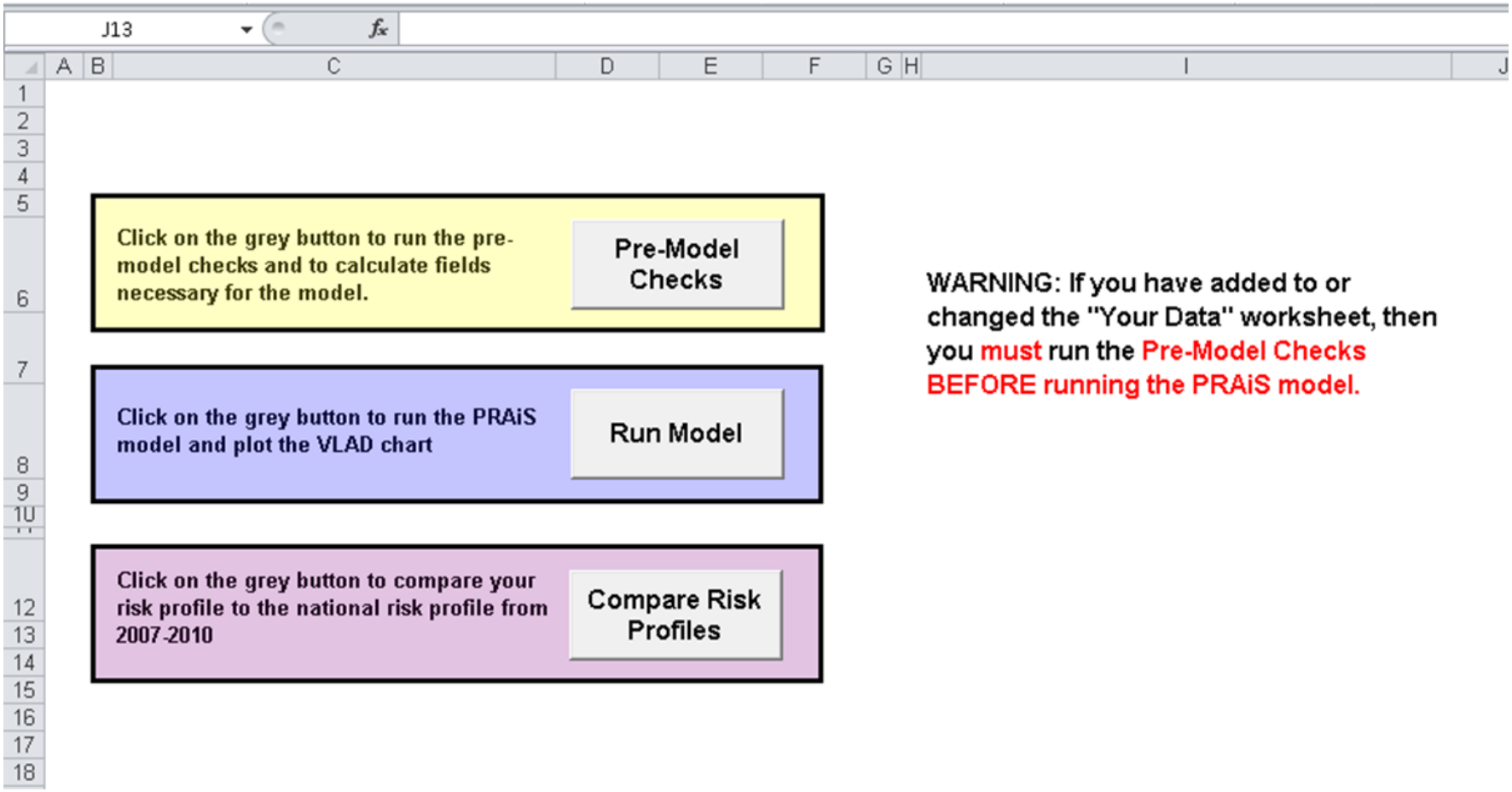
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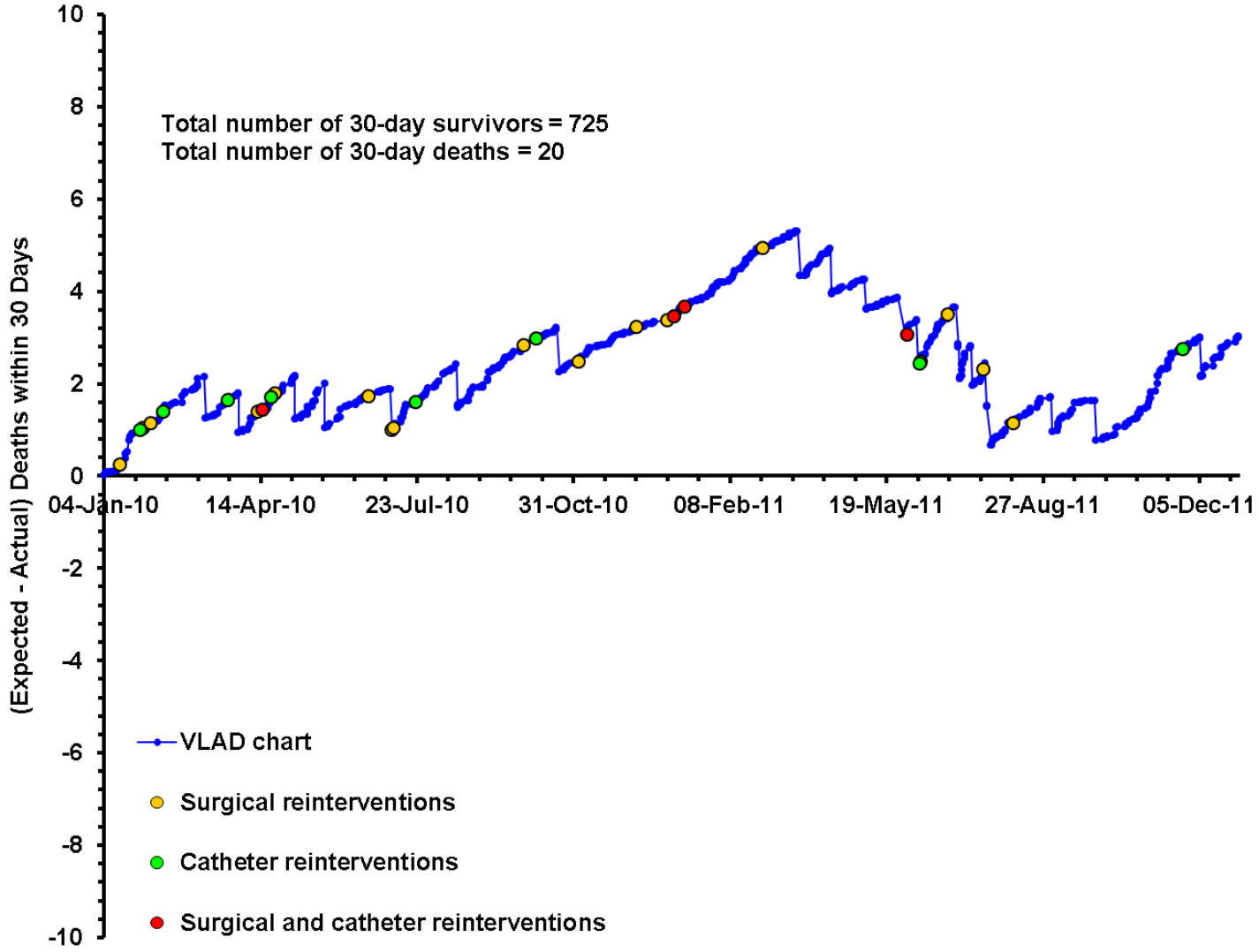
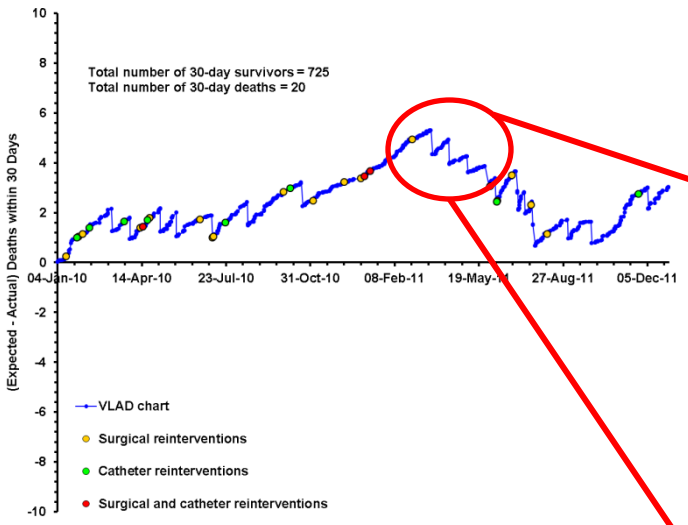
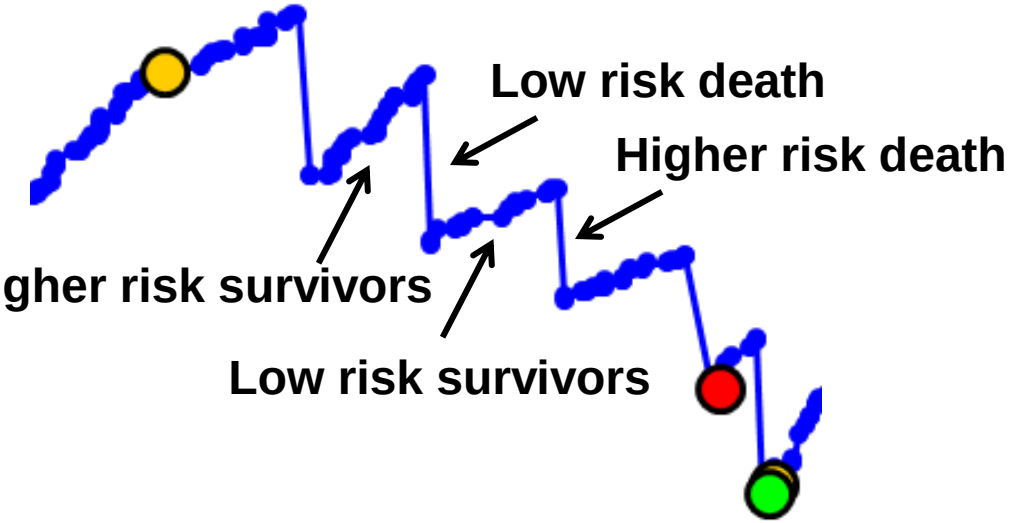
Illustrative VLAD output

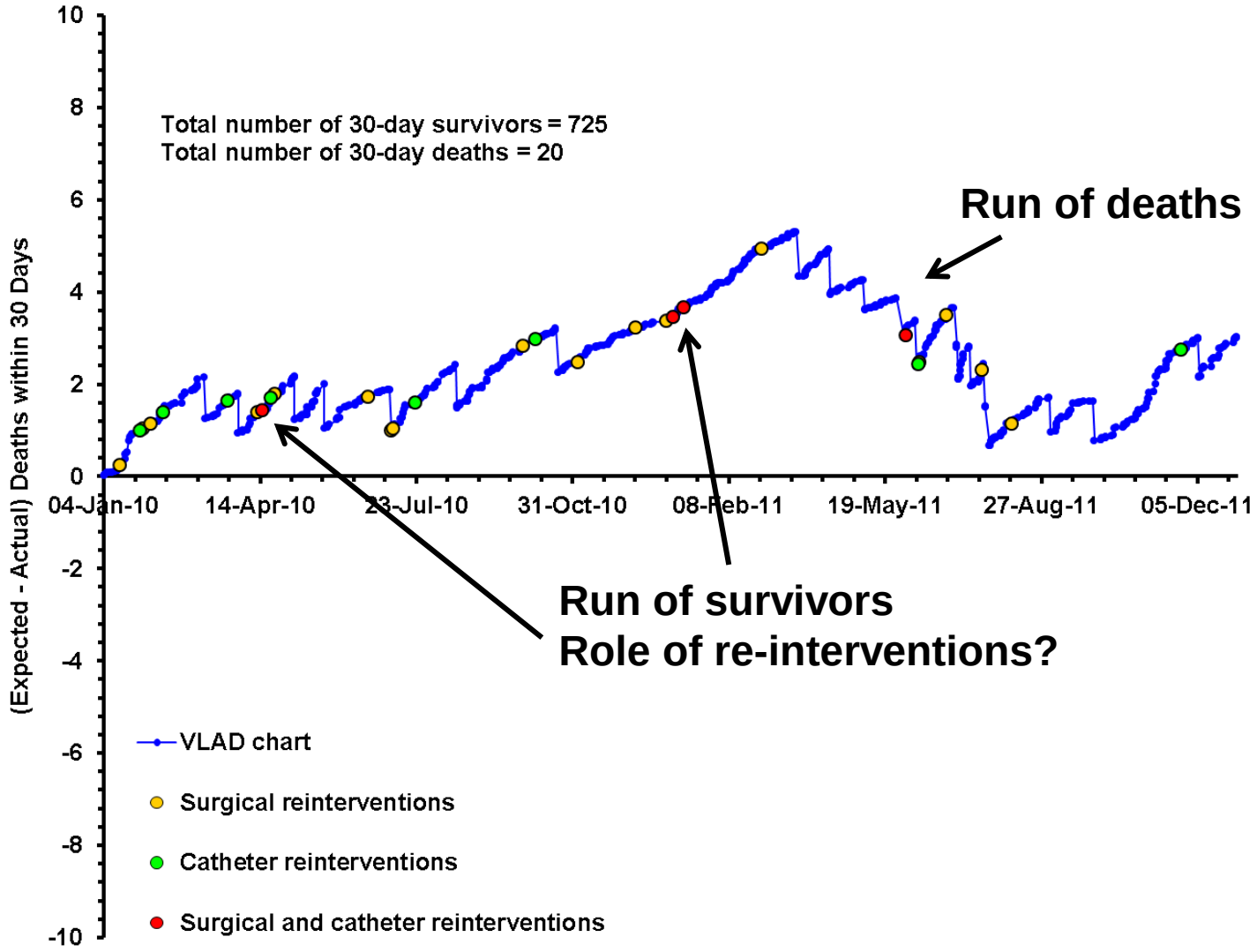


Illustrative VLAD output





Illustrative VLAD output



How did it happen?

Enthusiasm from clinical community:

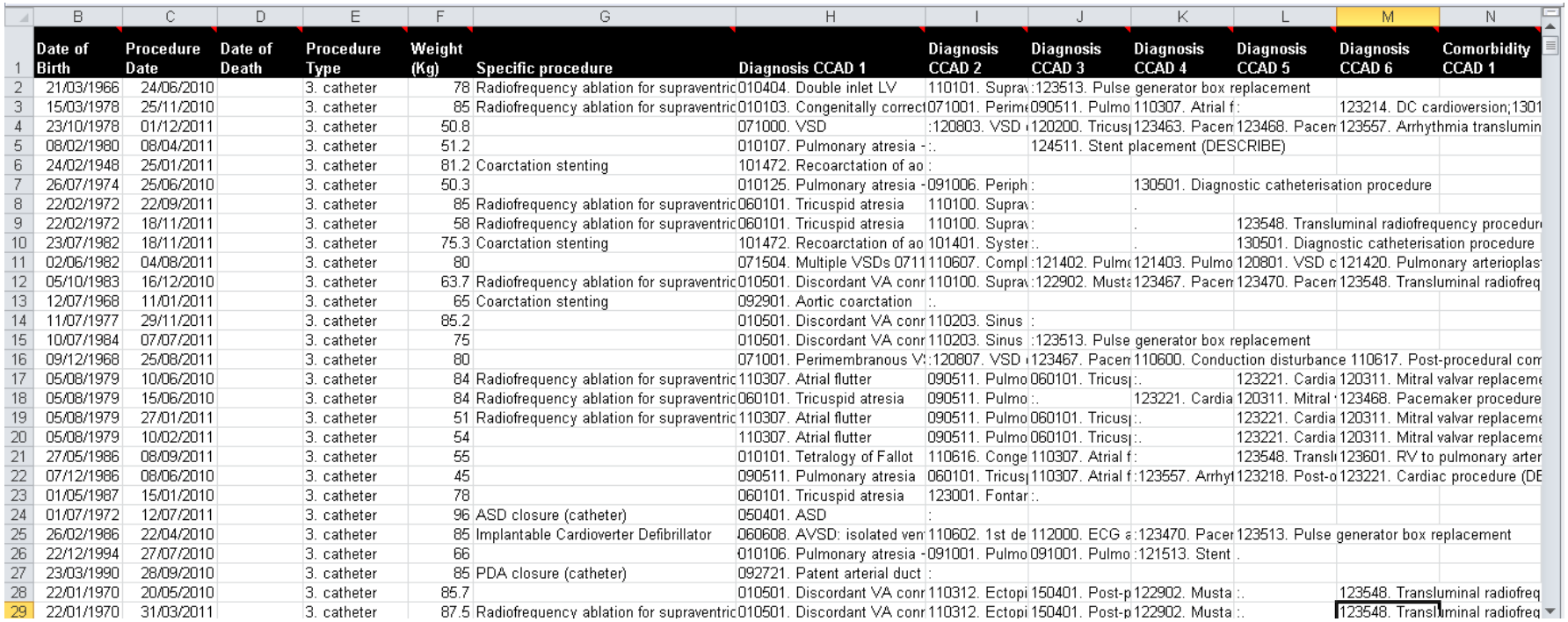
- Gave updates on risk model development to clinical community at annual meetings
- Generated support from them and within national audit (who funded pilot)
- Critical to recruiting willing units for the pilot – which started very quickly after model development finished.

How did it happen?

Key input from unit data managers:

- Allow for a variety of data formats
- Need to be able to copy and paste directly from existing data

Making it simple to use



	B	C	D	E	F	G	H	I	J	K	L	M	N
1	Date of Birth	Procedure Date	Date of Death	Procedure Type	Weight (Kg)	Specific procedure	Diagnosis CCAD 1	Diagnosis CCAD 2	Diagnosis CCAD 3	Diagnosis CCAD 4	Diagnosis CCAD 5	Diagnosis CCAD 6	Comorbidity CCAD 1
2	21/03/1966	24/06/2010		3. catheter	78	Radiofrequency ablation for supraventric	010404. Double inlet LV	110101. Supra	:123513. Pulse generator box replacement				
3	15/03/1978	25/11/2010		3. catheter	85	Radiofrequency ablation for supraventric	010103. Congenitally correct	071001. Perime	090511. Pulmo	110307. Atrial f	:	123214. DC cardioversion;1301	
4	23/10/1978	01/12/2011		3. catheter	50.8		071000. VSD	:120803. VSD	120200. Tricus	123463. Pacer	123468. Pacer	123557. Arrhythmia translumin	
5	08/02/1980	08/04/2011		3. catheter	51.2		010107. Pulmonary atresia -	:.	124511. Stent placement (DESCRIBE)				
6	24/02/1948	25/01/2011		3. catheter	81.2	Coarctation stenting	101472. Recoarctation of ao	:					
7	26/07/1974	25/06/2010		3. catheter	50.3		010125. Pulmonary atresia -	091006. Periph	:	130501. Diagnostic catheterisation procedure			
8	22/02/1972	22/09/2011		3. catheter	85	Radiofrequency ablation for supraventric	060101. Tricuspid atresia	110100. Supra	:	.			
9	22/02/1972	18/11/2011		3. catheter	58	Radiofrequency ablation for supraventric	060101. Tricuspid atresia	110100. Supra	:	.	123548. Transluminal radiofrequency procedur		
10	23/07/1982	18/11/2011		3. catheter	75.3	Coarctation stenting	101472. Recoarctation of ao	101401. Syster	:.	.	130501. Diagnostic catheterisation procedure		
11	02/06/1982	04/08/2011		3. catheter	80		071504. Multiple VSDs 0711	110607. Compl	:121402. Pulm	121403. Pulmo	120801. VSD c	121420. Pulmonary arterioplas	
12	05/10/1983	16/12/2010		3. catheter	63.7	Radiofrequency ablation for supraventric	010501. Discordant VA conr	110100. Supra	:122902. Musta	123467. Pacer	123470. Pacer	123548. Transluminal radiofreq	
13	12/07/1968	11/01/2011		3. catheter	65	Coarctation stenting	092901. Aortic coarctation	:.					
14	11/07/1977	29/11/2011		3. catheter	85.2		010501. Discordant VA conr	110203. Sinus	:				
15	10/07/1984	07/07/2011		3. catheter	75		010501. Discordant VA conr	110203. Sinus	:123513. Pulse generator box replacement				
16	09/12/1968	25/08/2011		3. catheter	80		071001. Perimembranous V	:120807. VSD	123467. Pacer	110600. Conduction disturbance		110617. Post-procedural cor	
17	05/08/1979	10/06/2010		3. catheter	84	Radiofrequency ablation for supraventric	110307. Atrial flutter	090511. Pulmo	060101. Tricus	:.	123221. Cardia	120311. Mitral valvar replaceme	
18	05/08/1979	15/06/2010		3. catheter	84	Radiofrequency ablation for supraventric	060101. Tricuspid atresia	090511. Pulmo	:.	123221. Cardia	120311. Mitral v	123468. Pacemaker procedure	
19	05/08/1979	27/01/2011		3. catheter	51	Radiofrequency ablation for supraventric	110307. Atrial flutter	090511. Pulmo	060101. Tricus	:.	123221. Cardia	120311. Mitral valvar replaceme	
20	05/08/1979	10/02/2011		3. catheter	54		110307. Atrial flutter	090511. Pulmo	060101. Tricus	:.	123221. Cardia	120311. Mitral valvar replaceme	
21	27/05/1986	08/09/2011		3. catheter	55		010101. Tetralogy of Fallot	110616. Conge	110307. Atrial f	:	123548. Transl	123601. RV to pulmonary arter	
22	07/12/1986	08/06/2010		3. catheter	45		090511. Pulmonary atresia	060101. Tricus	110307. Atrial f	:123557. Arrhyt	123218. Post-o	123221. Cardiac procedure (DE	
23	01/05/1987	15/01/2010		3. catheter	78		060101. Tricuspid atresia	123001. Fontar	:.				
24	01/07/1972	12/07/2011		3. catheter	96	ASD closure (catheter)	050401. ASD	:					
25	26/02/1986	22/04/2010		3. catheter	85	Implantable Cardioverter Defibrillator	060608. AVSD: isolated ven	110602. 1st de	112000. ECG a	:123470. Pacer	123513. Pulse generator box replacement		
26	22/12/1994	27/07/2010		3. catheter	66		010106. Pulmonary atresia -	091001. Pulmo	091001. Pulmo	:121513. Stent	.		
27	23/03/1990	28/09/2010		3. catheter	85	PDA closure (catheter)	092721. Patent arterial duct	:					
28	22/01/1970	20/05/2010		3. catheter	85.7		010501. Discordant VA conr	110312. Ectopi	150401. Post-p	122902. Musta	:.	123548. Transluminal radiofreq	
29	22/01/1970	31/03/2011		3. catheter	87.5	Radiofrequency ablation for supraventric	010501. Discordant VA conr	110312. Ectopi	150401. Post-p	122902. Musta	:.	123548. Transluminal radiofreq	

Data managers can paste their data directly into a worksheet – this is where developing the risk model with use in mind was invaluable.

E.g. We use date of death to calculate outcome – this was discussed with data managers.

Making it simple to use

1	Reason for removal	Patient Identifier	Date of Birth	Procedure Date	Date of Death	Procedure Type
2	We think this patient was over 16 at the time of their procedure	1	21/03/1966	20/04/2010		3. catheter
3	We think this patient was over 16 at the time of their procedure	2	15/03/1978	21/09/2010		3. catheter
4	We think this patient was over 16 at the time of their procedure	3	23/10/1978	27/09/2011		3. catheter
5	We think this patient was over 16 at the time of their procedure	4	08/02/1980	02/02/2011		3. catheter
6	We think this patient was over 16 at the time of their procedure	5	24/02/1948	21/11/2010		3. catheter
7	We think this patient was over 16 at the time o			1/04/2010		3. catheter
8	We think this patient was over 16 at the time o			9/07/2011		3. catheter
9	We think this patient was over 16 at the time o			4/09/2011		3. catheter
10	We think this patient was over 16 at the time of their procedure	9	23/07/1982	14/09/2011		3. catheter
11	We think this patient was over 16 at the time of their procedure	10	02/06/1982	31/05/2011		3. catheter
12	Patient only had catheter procedure(s)	25	22/12/1994	23/05/2010		3. catheter
13	We think this patient was over 16 at the time of their procedure	12	12/07/1968	07/11/2010		3. catheter
14	We think this patient was over 16 at the time of their procedure	13	11/07/1977	25/09/2011		3. catheter
15	We think this patient was over 16 at the time of their procedure	14	10/07/1984	03/05/2011		3. catheter
16	Patient only had catheter procedure(s)	15	02/02/1995	14/01/2010		3. catheter
17	We think this record is not a cardiac procedure	16	27/05/2003	15/06/2011		3. catheter
18	We think this patient was over 16 at the time of their procedure	17	05/08/1979	11/04/2010		3. catheter
19	We think this patient was over 16 at the time of their procedure	18	05/08/1979	23/11/2010		3. catheter
20	We think this patient was over 16 at the time of their procedure	19	05/08/1979	07/12/2010		3. catheter
21	We think this patient was over 16 at the time of their procedure	20	27/05/1986	05/07/2011		3. catheter
22	We think this patient was over 16 at the time of their procedure	21	07/12/1986	04/04/2010		3. catheter
23	We think this patient was over 16 at the time of their procedure	22	01/05/1987	11/11/2009		3. catheter
24	We think this patient was over 16 at the time of their procedure	23	01/07/1972	08/05/2011		3. catheter
25	We think this patient was over 16 at the time of their procedure	24	26/02/1986	16/02/2010		3. catheter
26	Patient only had catheter procedure(s)	25	22/12/1994	23/05/2010		3. catheter
27	We think this patient was over 16 at the time of their procedure	26	23/03/1990	25/07/2010		3. catheter

We do all data exclusions

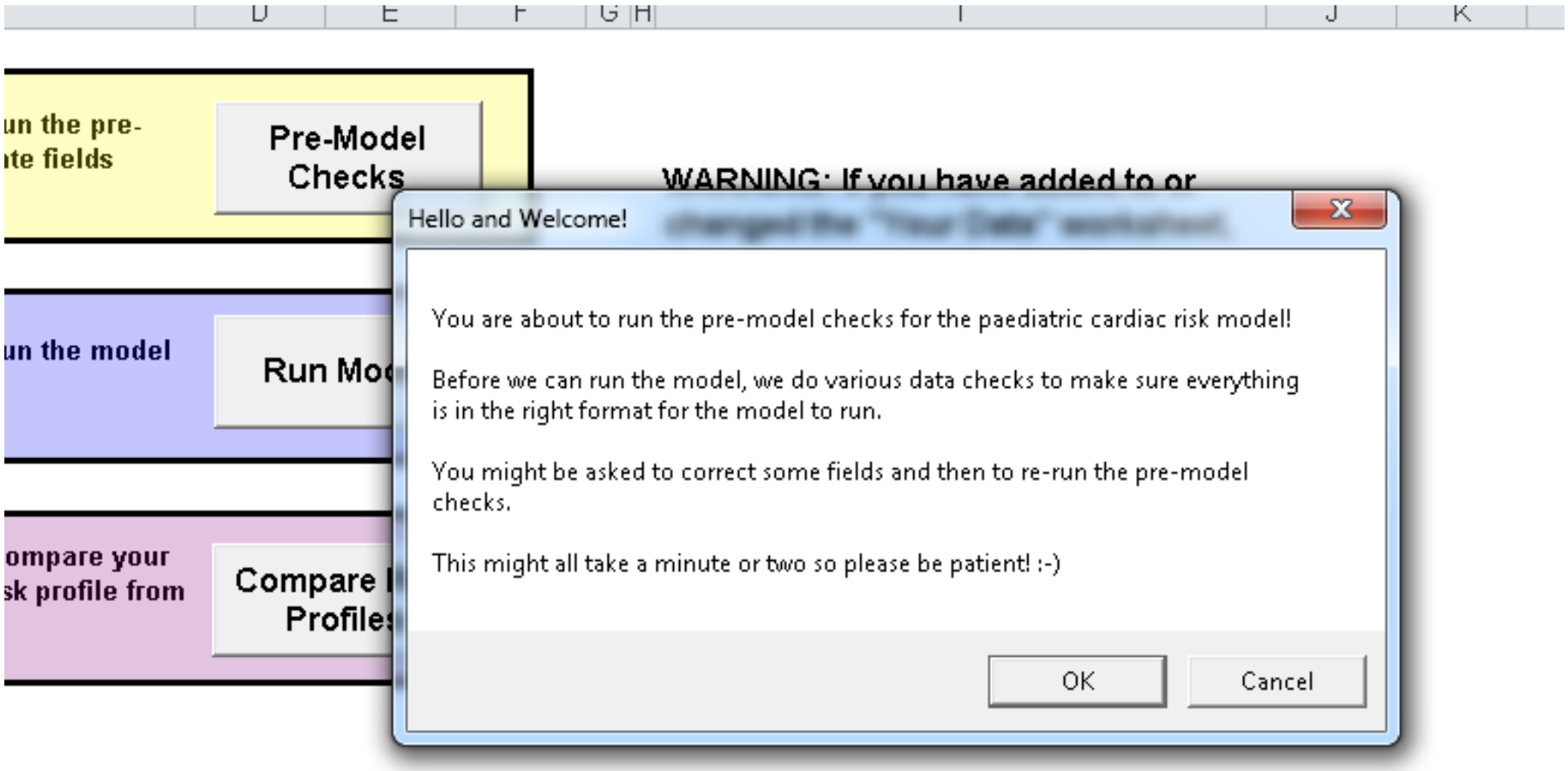
*** Note: dates have been changed**

How did it happen?

Key input from unit data managers:

- Allow for a variety of data formats
- Need to be able to copy and paste directly from existing data
- As intuitive as possible to use (although comprehensive instructions available)

Making it simple to use



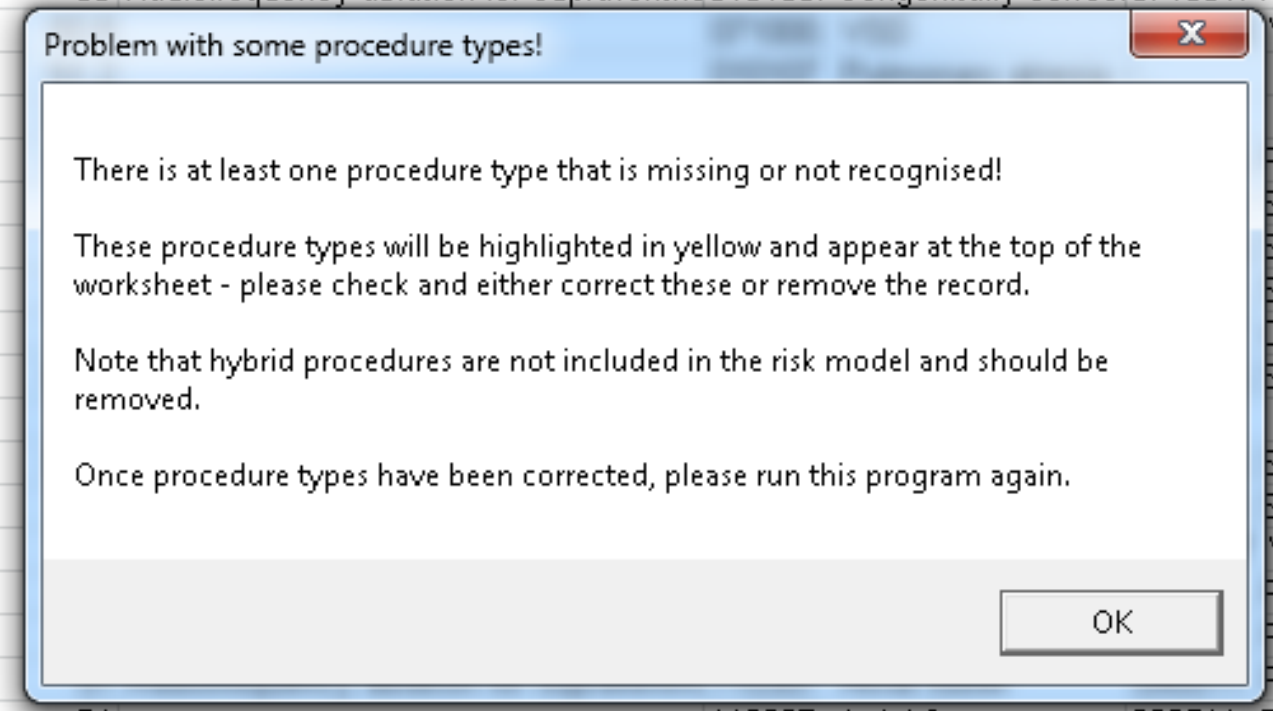
How did it happen?

Key input from unit data managers:

- Allow for a variety of data formats
- Need to be able to copy and paste directly from existing data
- As intuitive as possible to use (although comprehensive instructions available)
- Needs good error handling and data manipulation

Making it simple to use

Type	(Kg)	Specific procedure	Diagnosis CCAD 1	CCAD 2	CC
7. BAD PROC	78	Radiofrequency ablation for supraventric	010404. Double inlet LV	110101. Supra	:12
3. catheter	85	Radiofrequency ablation for supraventric	010103. Congenitally correct	071001. Perime	090
3. catheter				VSD	120
3. catheter					124
3. catheter					
3. catheter				Periph	:
3. catheter				Supra	:
3. catheter				Supra	:
3. catheter				Syster	:.
3. catheter				Compl	:12
3. catheter				Supra	:12
3. catheter					
3. catheter				Sinus	:
3. catheter				Sinus	:12
3. catheter				VSD	123
3. catheter				Pulmo	060
3. catheter				Pulmo	:.
3. catheter				Pulmo	060
3. catheter	54		110307. Atrial flutter	090511. Pulmo	060
3. catheter	55		010101. Tetralogy of Fallot	110616. Conge	110
3. catheter	45		090511. Pulmonary atresia	060101. Tricus	110



How did it happen?

Key input from unit data managers:

- Allow for a variety of data formats
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Barriers to use are HIGH – only needs to be a bit inconvenient or break once to deter data managers from adding it to their workload.

Risk models take a long time to develop – and then risk not be used because not well implemented.

How did it happen?

Key input from clinicians:

- Write out all deaths so that they can be quickly looked at

Adding information

	A	B	C	D	E	F	G	H	I	
1	Patient Identifier	Date of Birth	Procedure Date	Date of Death	Procedure Type	Weight (Kg)	Specific procedure	Diagnosis CCAD 1	Diagnosis CCAD 2	Dia CC
2	6	03/02/2002	24/03/2010	08/04/2010	1. bypass	24.2	Aortic root replacement (not F	101442. Ascending aorta ane		
3	9	05/05/2010	14/04/2010	29/04/2010	1. bypass	0.8	PDA ligation (surgical)	092721. Patent arterial duct ı		
4	544	20/06/2010	20/05/2010	04/06/2010	1. bypass	2.38	Isolated coarctation repair	070842. Functionally univenti	092911. Ao	
5	345	28/06/2010	08/06/2010	23/06/2010	2. non-bypass	0.75	PDA ligation (surgical)	092721. Patent arterial duct ı		
6	555	04/06/2009	21/07/2010	05/08/2010	1. bypass	7.7	Pulmonary atresia VSD repai	010125. Pulmonary atresia +	:123104. M	122
7	43	16/10/2010	01/09/2010	16/09/2010	2. non-bypass	1.8	Isolated coarctation repair	092901. Aortic coarctation		
8	223	24/12/2010	05/11/2010	20/11/2010	1. bypass	3.81		010309. AV and-or VA conne	020102. De	060
9	66	12/03/2011	08/04/2011	23/04/2011	1. bypass	2.6	Aortic valve replacement - Ro	091592. Aortic stenosis	101012. En	103
10	17	02/08/2009	28/04/2011	13/05/2011	1. bypass	8.56		070530. Subpulmonary stenc	090592. Pu	071
11	189	21/12/2010	20/05/2011	04/06/2011	1. bypass	7.4	Tetralogy repair	010101. Tetralogy of Fallot		
12	456	22/04/2011	14/06/2011	29/06/2011	1. bypass	4.7	Bidirectional cavopulmonary s	091513. Aortic valvar stenosi	101012. En	:12
13	33	07/08/2011	22/06/2011	07/07/2011	2. non-bypass	2.7	Isolated coarctation repair	092800. Aortic arch abnorma		
14	356	17/12/2005	18/07/2011	02/08/2011	1. bypass	18	Subvalvar aortic stenosis repa	092901. Aortic coarctation	071001. Pe	070
15	115	16/07/2011	19/07/2011	03/08/2011	2. non-bypass	1.2	PDA ligation (surgical)	092721. Patent arterial duct ı	102202. Pre	
16	276	03/03/1999	27/07/2011	11/08/2011	1. bypass	81	Subvalvar aortic stenosis repa	070900. Subaortic stenosis		
17	334	24/09/2011	05/08/2011	20/08/2011	1. bypass	3.2	Norwood procedure (Stage 1)	010109. Hypoplastic left hear		
18	485	30/06/2011	08/08/2011	23/08/2011	1. bypass	4.9	Aortopulmonary window repai	090401. Aortopulmonary win		
19	377	04/03/2010	16/09/2011	01/10/2011	1. bypass	10.1	Norwood procedure (Stage 1)	071001. Perimembranous VS	091530. Ao	
20	76	30/10/2007	14/10/2011	29/10/2011	1. bypass	25	ASD repair	050401. Interatrial communic		
21	277	10/11/2011	20/12/2011	04/01/2012	1. bypass	5.6	Aortic valve replacement - Ro	050402. Atrial septal defect (		
22										

All deaths written out including comprehensive information

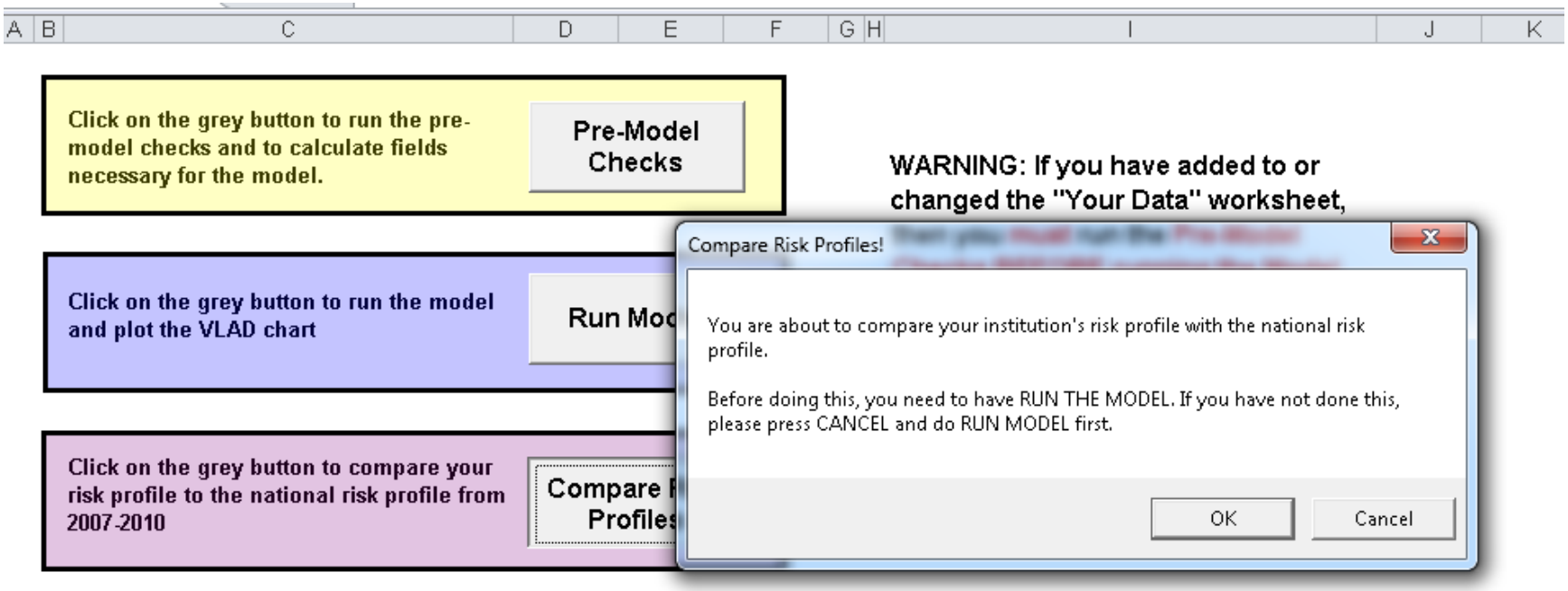
*** Note: dates have been changed**

How did it happen?

Key input from clinicians:

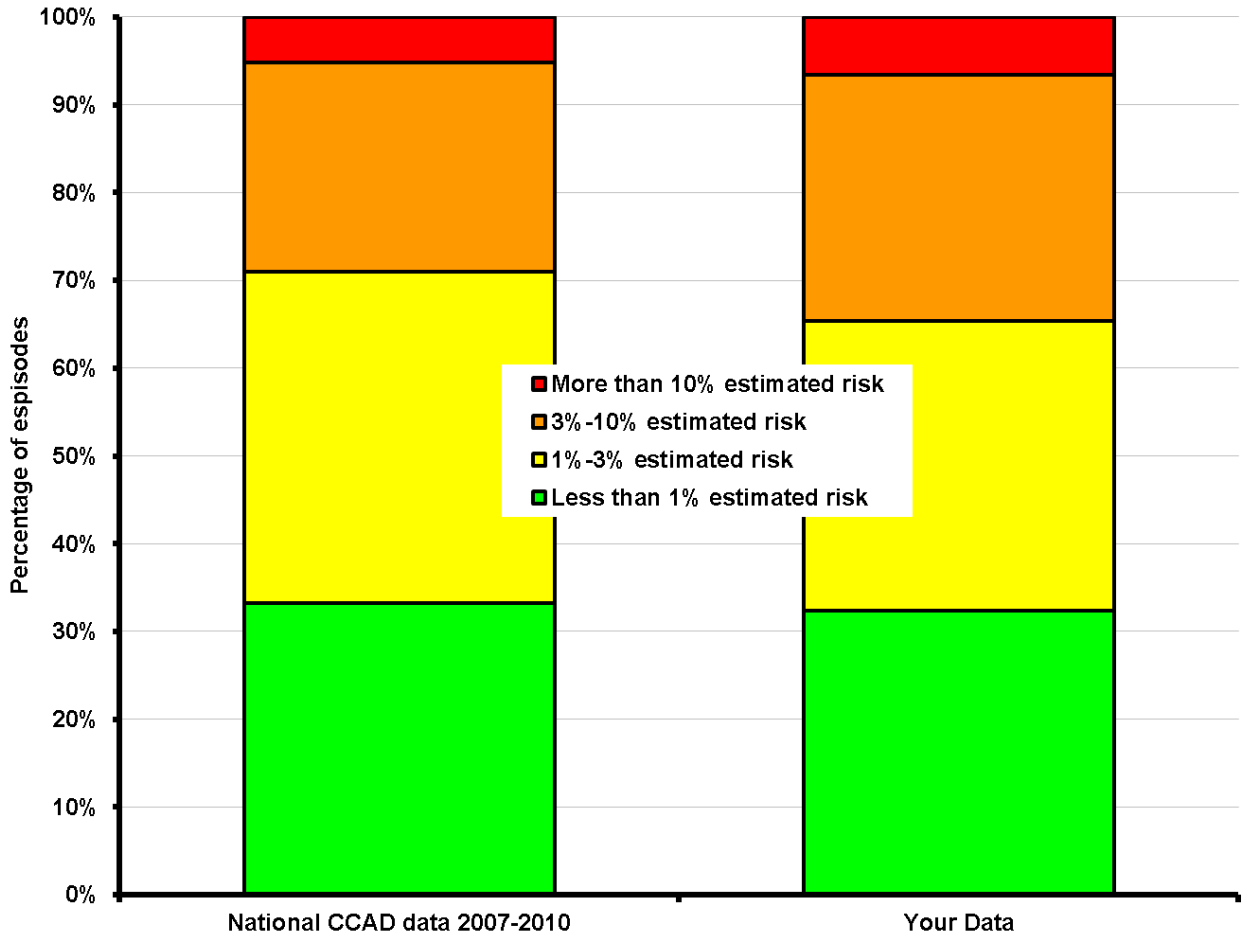
- Write out all deaths so that they can be quickly looked at
- Add total number of survivors and deaths to the VLAD chart
- Have simple information on the unit's case mix

Adding information



We added option to compare a unit's risk profiles to the national average

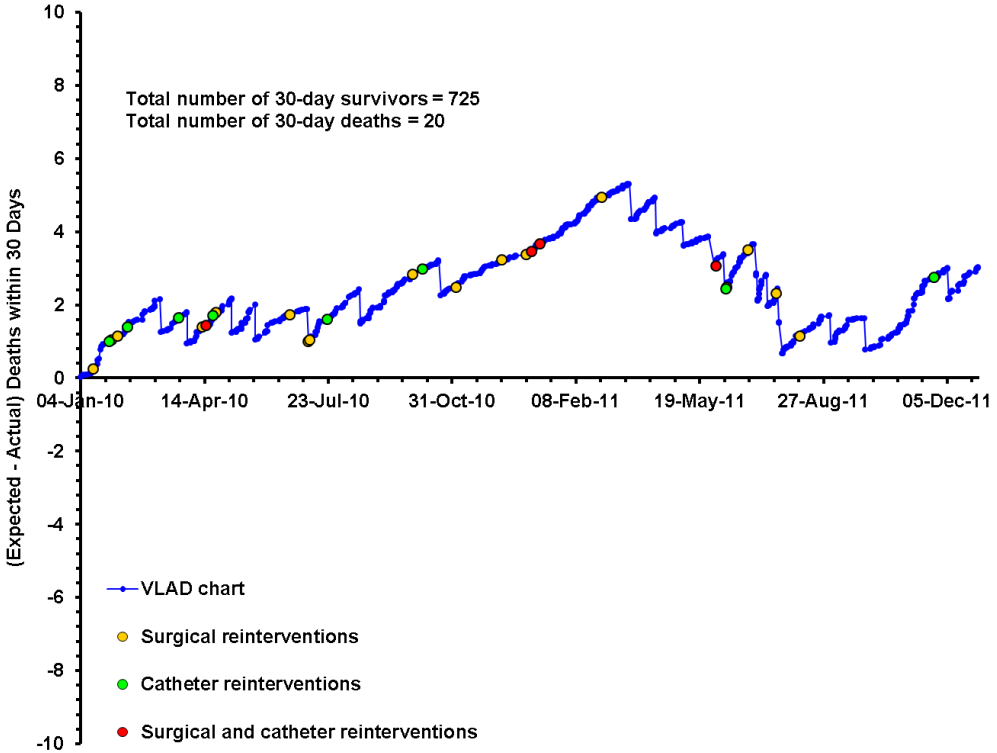
Adding information



Lessons learned 1

Clinicians interpreted being near zero line as “indifferent performance”

“Why do deaths drop so much more than a survival rises? It’s not fair”



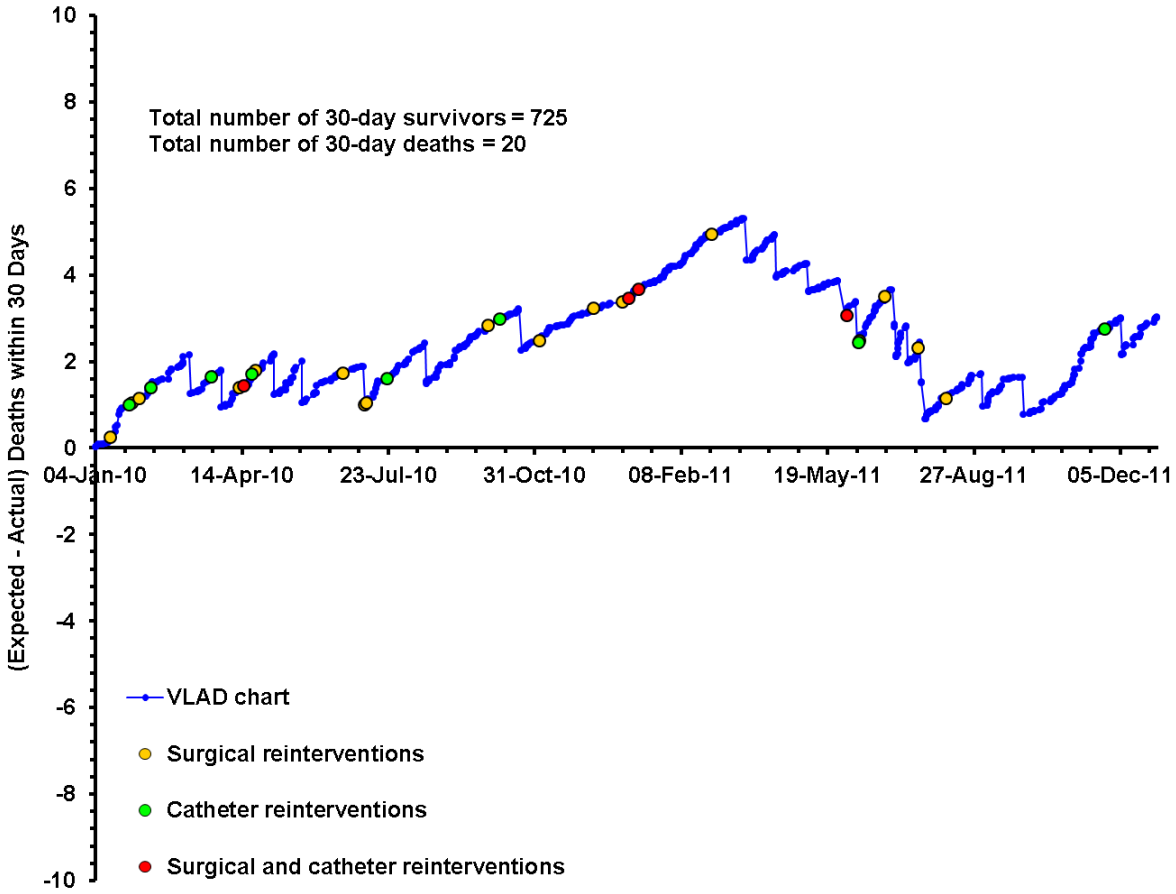
Lessons learned 2

Important to show clinicians the impact of risk factors on estimated risk – shows both the advantages of case-mix adjustment and the limitations.

Specific procedure	Weight (Kg)	Comorbidity	Age band	Age	Risk of death
Pulmonary atresia VSD repair	8	0	Child	13 months	2.2%
Pulmonary atresia VSD repair	5.2	1	Child	17 months	4.4%
Pulmonary atresia VSD repair	7.28	0	Infant	11 months	5.4%
Pulmonary atresia VSD repair	5.7	1	Infant	7 months	9.6%
PDA ligation (surgical)	3	0	Infant	45 days	1.8%
PDA ligation (surgical)	1	0	Neonate	29 days	3.0%
PDA ligation (surgical)	0.72	1	Infant	60 days	3.4%
PDA ligation (surgical)	1	1	Neonate	22 days	5.3%
PDA ligation (surgical)	0.6	1	Neonate	19 days	5.4%
PDA ligation (surgical)	0.6	1	Neonate	28 days	5.4%
Tetralogy repair	18.7	0	Child	6.5 years	0.7%
Tetralogy repair	6.7	0	Infant	8 months	1.7%
Tetralogy repair	6.74	1	Infant	6 months	3.0%

Lessons learned 3

Clinicians raised some questions about ownership of data and role of monitoring – in-house or national? Published or private?



Lessons learned 4

Sustainability:

We developed the risk model in collaboration with clinical community with a view to eventual use and a pilot.

We did not explicitly plan for how to move from the pilot to routine national use:

- Who will pay for maintaining and supporting software?
- Will we give software away or sell it? If former, who pays for the work?
- What about future updates?
- How do we publicise the model? Who pays for the time?
- Is any of this academic research? What does being an academic OR researcher mean?

Conclusions

- The pilot was successful – prototype software developed, distributed to units and being used in at least 2 out of the 3.

- Input of clinicians and data managers crucial to success of pilot

- Need to be aware of barriers and sensitivities to use and plan for them

- Development of risk model needs to plan for routine use from the beginning

The end

Any Questions?