Congenital Heart Disease Network – South Wales and South West

Analysis of self-assessment against the new CHD Standards

Children's Level 3 Centres

September 2016

Response rate and overview

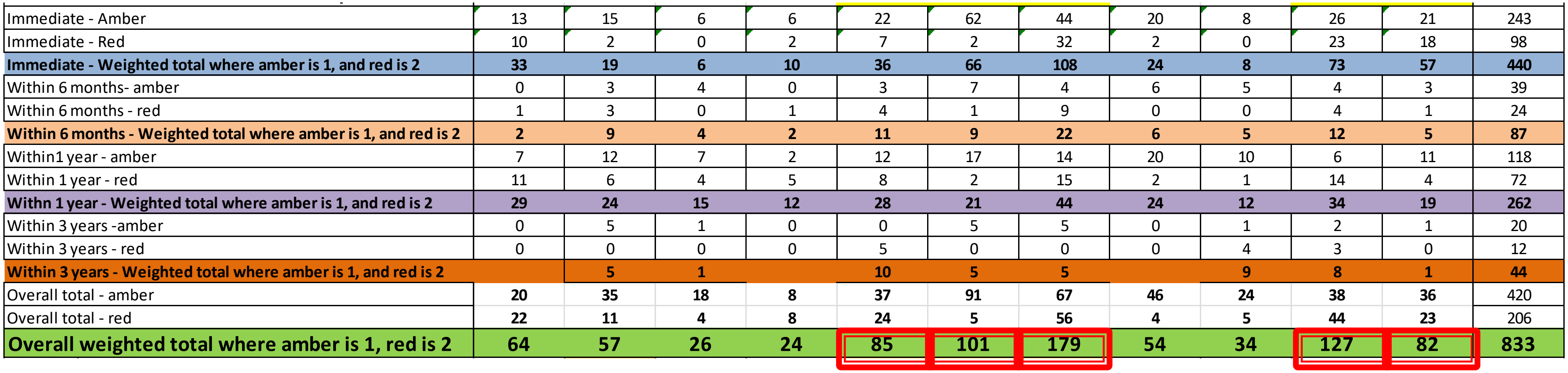
- 11 of 14 level 3 children's centres completed the self assessment: Royal Cornwall are due to complete in the next 2 weeks, Plymouth and Yeovil TBC
- Across the 11 Trusts, 1,352 (61%) standards were rated as green
- So, while there are some gaps to be addressed, this should be recognised as a really solid start point

Method to identify themes to be addressed

- Filter to only include standards that have been rated amber or red
- Sub-divide by timescale for implementation
- Identify those standards for which there are a high number of red/amber responses across the centres

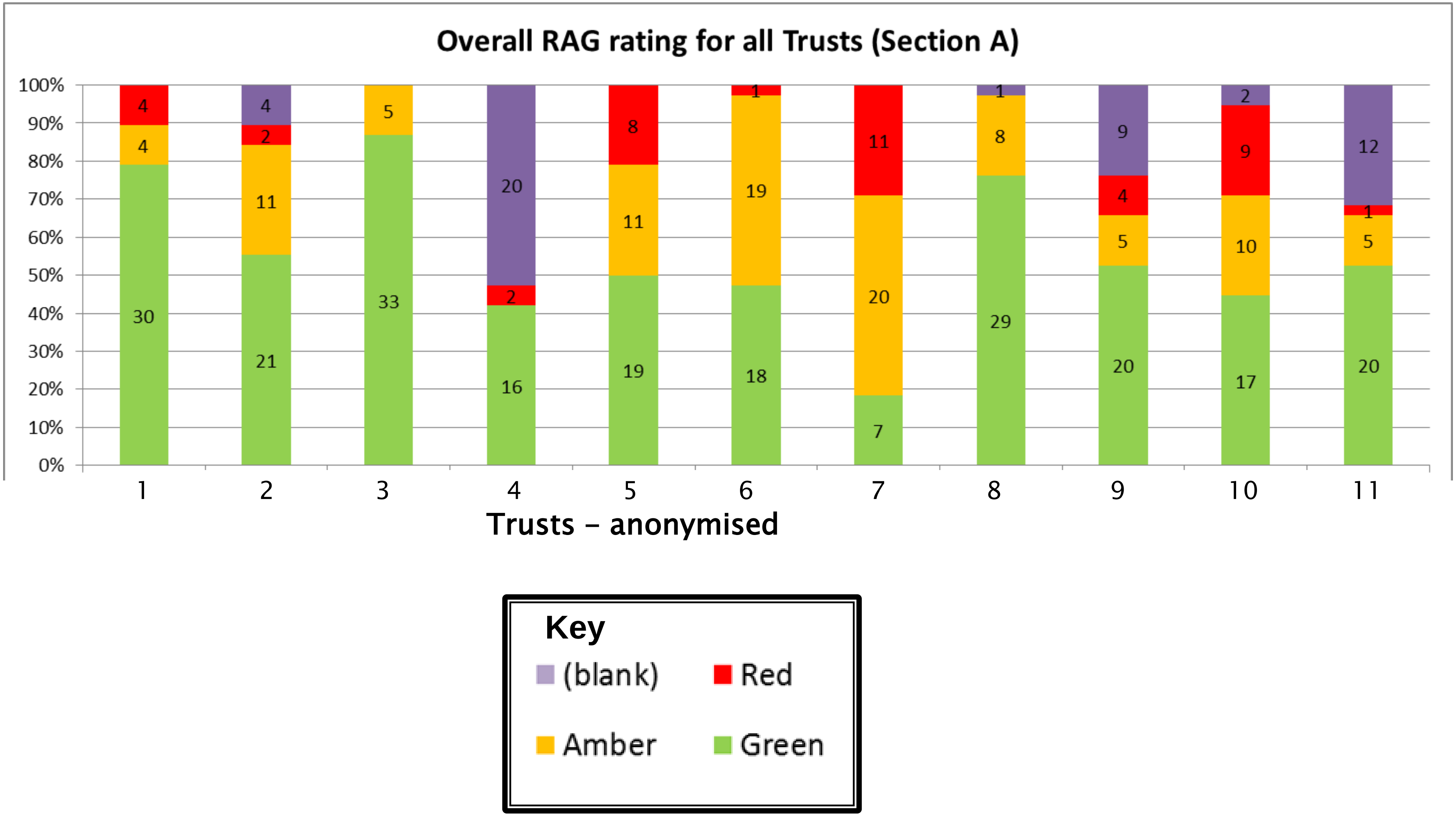
Overall RAG rating for all Trusts (All Standards)

All Trusts Overview



Immediate - Amber	13	15	6	6	22	62	44	20	8	26	21	243
Immediate - Red	10	2	0	2	7	2	32	2	0	23	18	98
Immediate - Weighted total where amber is 1, and red is 2	**33**	**19**	**6**	**10**	**36**	**66**	**108**	**24**	**8**	**73**	**57**	**440**
Within 6 months- amber	0	3	4	0	3	7	4	6	5	4	3	39
Within 6 months - red	1	3	0	1	4	1	9	0	0	4	1	24
Within 6 months - Weighted total where amber is 1, and red is 2	**2**	**9**	**4**	**2**	**11**	**9**	**22**	**6**	**5**	**12**	**5**	**87**
Within1 year - amber	7	12	7	2	12	17	14	20	10	6	11	118
Within 1 year - red	11	6	4	5	8	2	15	2	1	14	4	72
Withn 1 year - Weighted total where amber is 1, and red is 2	**29**	**24**	**15**	**12**	**28**	**21**	**44**	**24**	**12**	**34**	**19**	**262**
Within 3 years -amber	0	5	1	0	0	5	5	0	1	2	1	20
Within 3 years - red	0	0	0	0	5	0	0	0	4	3	0	12
Within 3 years - Weighted total where amber is 1, and red is 2		**5**	**1**		**10**	**5**	**5**		**9**	**8**	**1**	**44**
Overall total - amber	**20**	**35**	**18**	**8**	**37**	**91**	**67**	**46**	**24**	**38**	**36**	420
Overall total - red	**22**	**11**	**4**	**8**	**24**	**5**	**56**	**4**	**5**	**44**	**23**	206
Overall weighted total where amber is 1, red is 2	**64**	**57**	**26**	**24**	**85**	**101**	**179**	**54**	**34**	**127**	**82**	**833**

- There are a number of Trust who are further from the standards in terms of their self-assessments.
- However, it is worth noting that Trusts may have taken a different approach to self-assessing and may have scored themselves more harshly / leniently
- There may also be different areas of priority for the network – see next slides


Overall RAG rating for all Trusts (Section A)
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Trusts – anonymised
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Section A – Network Approach Key Gaps

Immediate:

- A14: Ability to access MDT & be involved in decision making via telemedicine, L2 centre to participate weekly
- A6: Access to a standardised electronic health record
- A8: Protocols / pathways to allow 24/7 availability of pre-operative risk assessment by a Congenital Heart team including a paediatrician with expertise

Within 6 months

- A13: Remote access to records at L1 centre
- A5: Protocols for transfer of patients requiring intervention

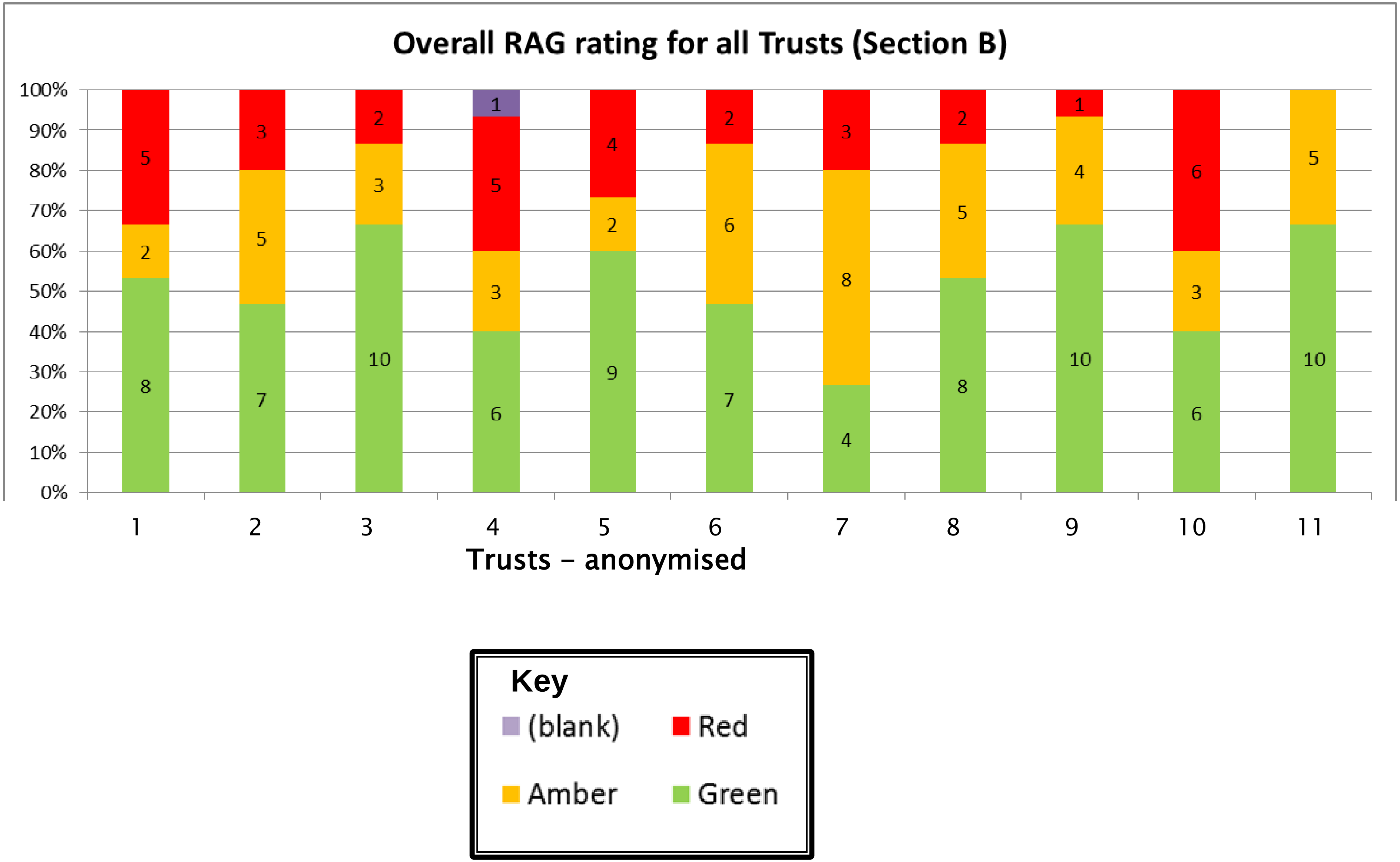
Within 1 year

- A15: Job planned capacity for PECs to attend 6 MDTs and annual meeting
- A16: PEC to form links with local primary care, community and DGHs
- A17: Registered child nurse with interest and training in cardiology
- A4: Pathway for OOH self-referrals ideally with electronic health passport
- A4: Joint clinics for PEC and specialist
- A4: Weekday cover for CHD from network of local PECs

Within 3 years

- A12: Telemedicine to allow echo, MDT, emergency referrals, transfer of images

Overall RAG rating for all Trusts (Section B)



Section B – Staffing & Skills

Immediate:

- B5: Level 1 children's CNS team will provide support, education and a link to L3 centres. L3 centres will have an identified link nurse

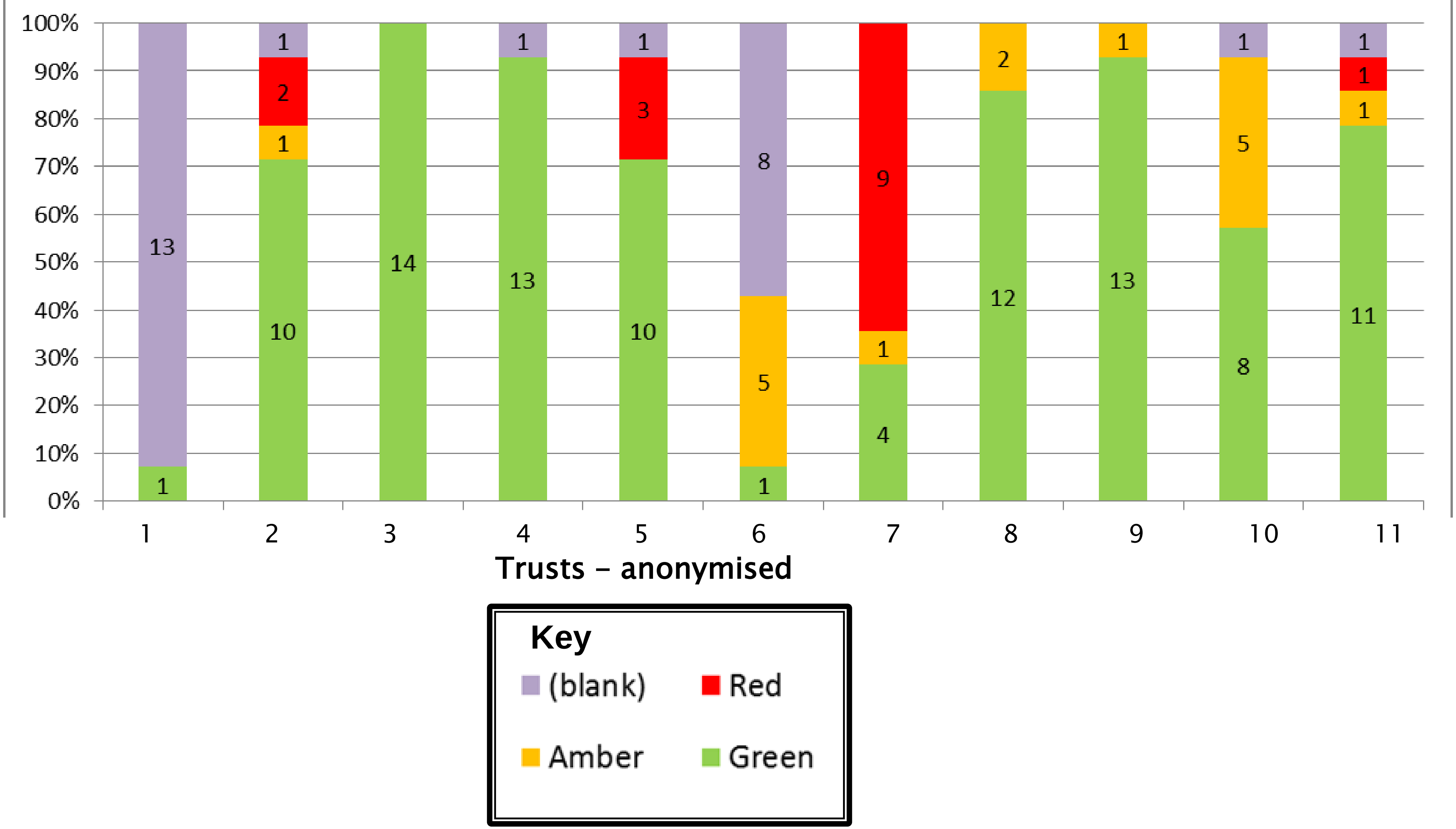
Within 6 months

- B6: Identified person to provide high quality data input for network database

Within 1 year

- B13: Each PEC must spend at least 20% of job plan on paediatric cardiology activity (inc SPA)
- B13: Each PEC must work with a designated paed cardiologist including running joint clinics
- B13: Each PEC will hold honorary contract at L1 centre and have opportunity to attend for clinics and educational development opportunities
- B2: Local Children’s Cardiology Centres must have locally designated registered children’s nurses with a specialist interest in paediatric cardiology, trained and educated in the assessment, treatment and care of cardiac children and young people.
- B4: Each Local Children’s Cardiology Centre must have a locally designated 0.25 WTE registered children’s nurse with a specialist interest to participate in cardiology clinics, provide support to inpatients and deal with requests for telephone advice.
- B8: Each Local Children’s Cardiology Centre must have a cardiac physiologist with training in congenital echocardiography.

Overall RAG rating for all Trusts (Section C)



Section C – Facilities

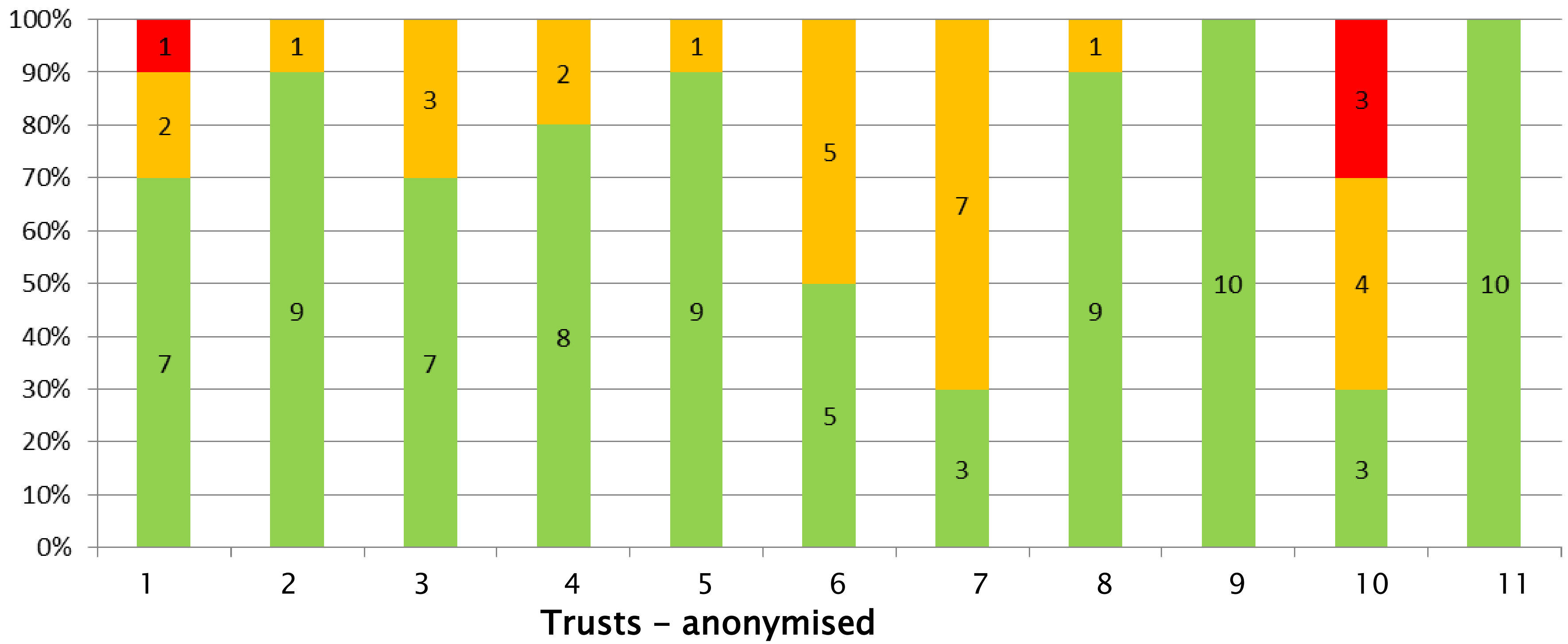
Immediate:

- C1: Dedicated child friendly facilities

Within 1 year

- C2: Accommodation for at least 2 family members to stay
- C2: Ability for 1 parent to stay with child 24 hours a day on ward
- C2: Facilities for meal prep
- C2: Family accommodation provided without charge

Overall RAG rating for all Trusts (Section D)



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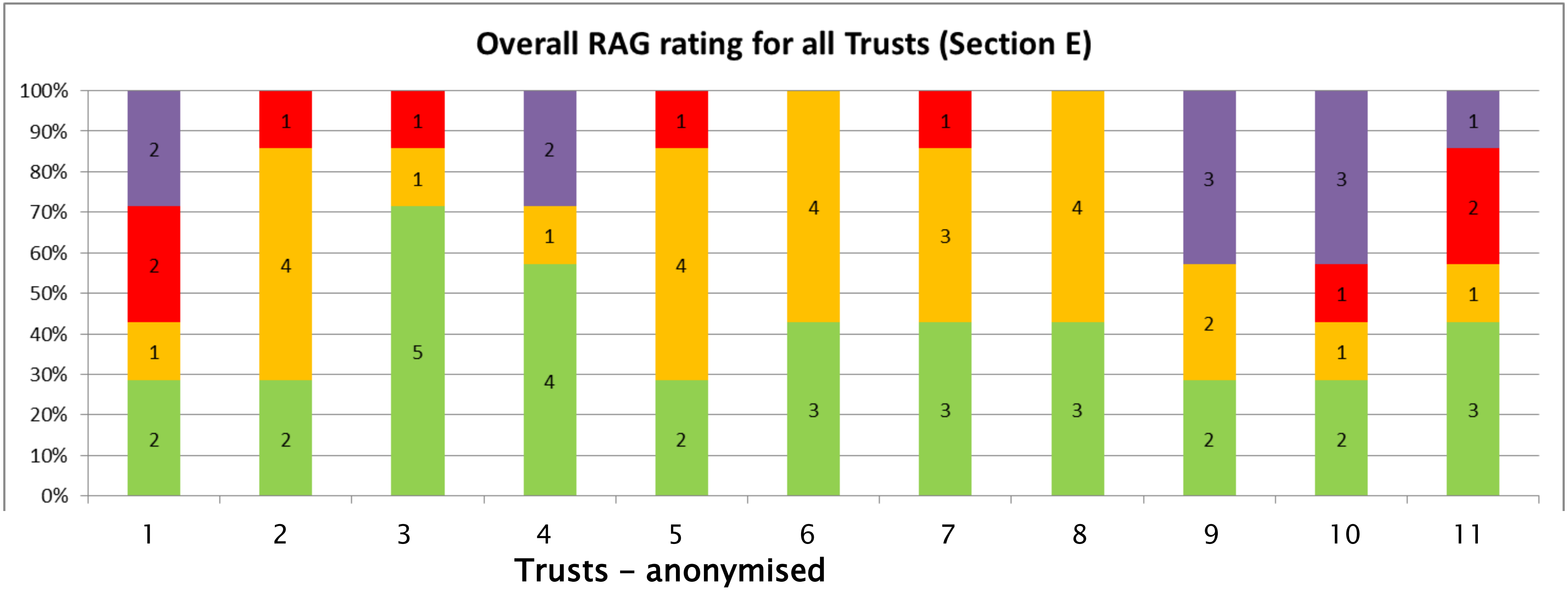
Section D – Interdependencies

Immediate:

- D5: Provision of standard non-invasive diagnostic imaging capabilities with access, across the network, to CT and MRI scanning. The exact range of equipment and investigations will be agreed with the Network.
- D5: Governance arrangements across network must ensure that the training and skills of all echocardiographic practitioners undertaking paediatric echocardiograms are kept up to date.
- D5: Must be able to access cardio-pulmonary exercise testing (CPEX) and the six-minute walk test in children and adolescents.
- D5: Must have access to include electrocardiography (ECG), Holter monitoring, event recording, standard exercise testing, ambulatory blood pressure monitoring and pacemaker follow-up and interrogation, 24 hour tapes, event recorders; and ambulatory blood pressure monitoring, as well as standard, and fetal echocardiography.
- D5: 24/7 access to modern echocardiographic equipment, maintained to British Society of Echocardiography (BSE) standards, with a selection of probes suitable for all age groups, including suitable fetal echo probes.
- D5: Facility to store and transfer digital recordings of radiological and echocardiographic images.

Overall RAG rating for all Trusts (Section E)



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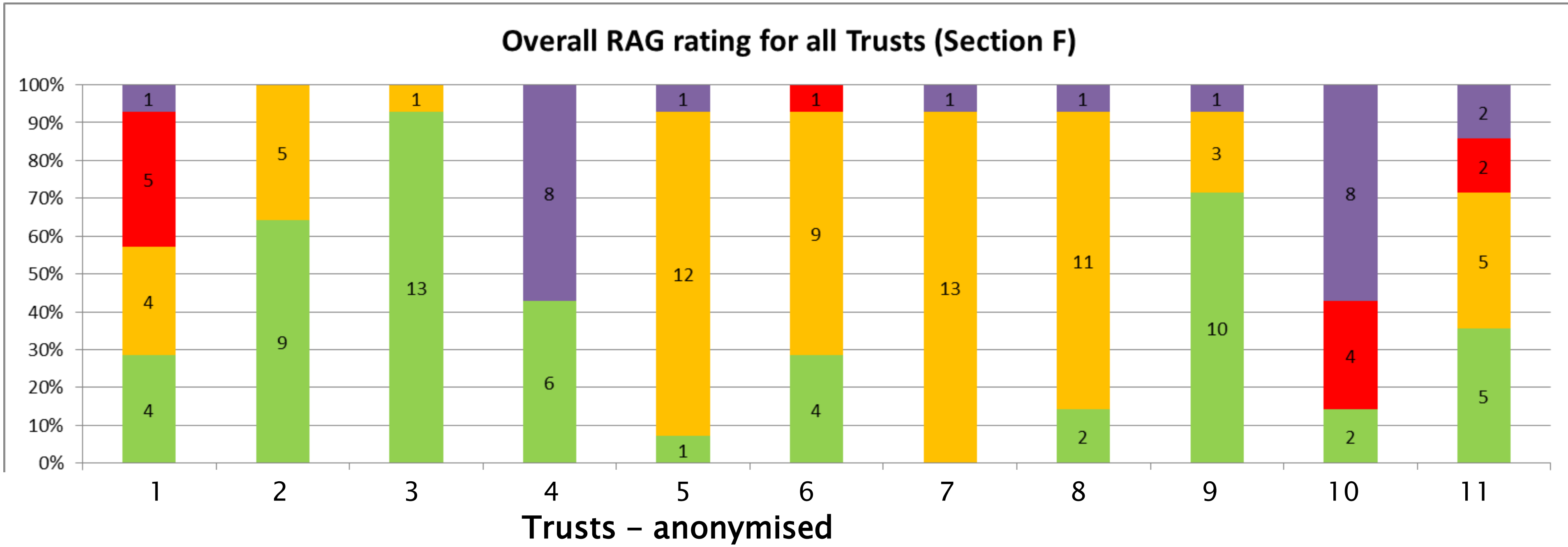
Section E – Training and Education

Immediate:

- E2: All members of the cardiac medical and nursing team will complete mandatory training on end-of-life care, breaking bad news and supporting children, young people and their families through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.
- E3: Each Local Children's Cardiology Centre must assist the Specialist Children's Surgical Centre in providing core curriculum level training as per the Joint Royal Colleges of Physicians' Training Board curriculum to all specialty doctors within their network catchment area.

Within 1 year:

- E4: Each Congenital Heart Network will have a formal annual training plan in place, which ensures ongoing education and professional development across the network for all healthcare professionals involved in the care of children and young people with congenital heart problems.
- E5: Sufficient Clinical Nurse Educators must be provided across each Congenital Heart Network to deliver standardised training and competency-based education programmes. They will be responsible for ensuring the continuing professional development of nursing staff in the Local Children's Cardiology Centre. The competency-based programme will focus on the acquisition of knowledge and skills such as clinical examination, assessment, diagnostic reasoning, treatment, facilitating and evaluating care, evidence-based practice and communication.
- E6: Nurses working within Local Children's Cardiology Centres must be offered allocated rotational time working in the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place.



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Section F – Organisation

Immediate:

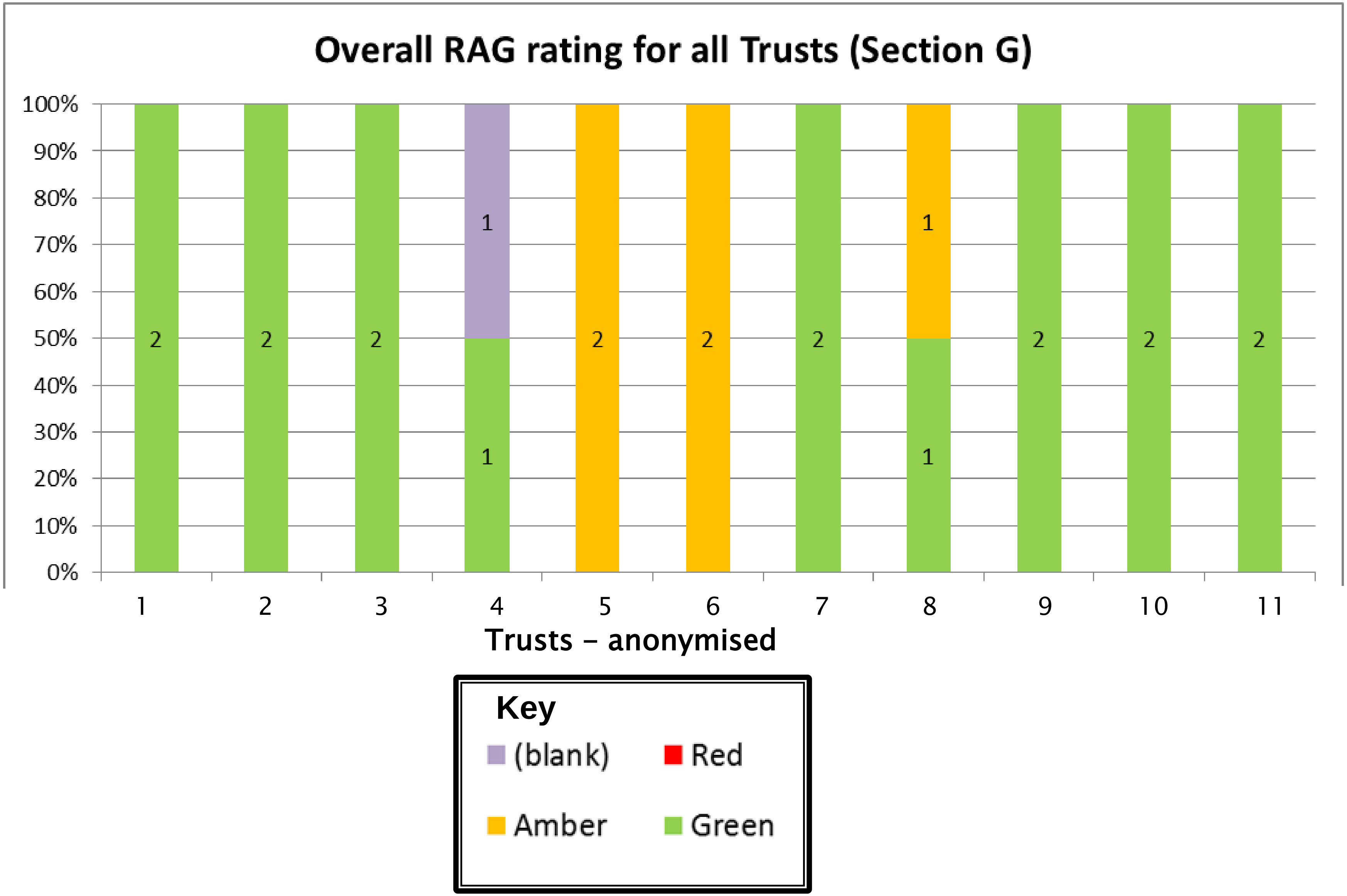
- F10: Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.
- F3: Each Local Children's Cardiology Centre will report on adverse incidents. In addition to contractual and national reporting requirements, Local Children's Cardiology Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.
- F5: Each Local Children's Cardiology Centre will participate in audits of clinical practice where recognised standards exist or improvements can be made. Participation in a programme of ongoing audit of clinical practice must be documented. At least one audit of clinical practice (or more if required by NHS commissioners) of demonstrable clinical significance will be undertaken annually.
- F6: Audits must take into account or link with similar audits across the network, other networks and other related specialties.
- F7: Each Local Children's Cardiology Centre must participate in relevant national programmes for audit and must submit data to the Specialist Children's Surgical or Specialist Children's Cardiology Centre on endocarditis so that this can be submitted to the National Institute for Cardiovascular Outcomes Research, including any emerging data requirements for morbidity audit.
- F9: Each Local Children's Cardiology Centre must work with the network to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Local Children's Cardiology Centres will follow mandatory National Institute for Health and Care Excellence guidance.

Within 6 months:

- F4: Each Local Children's Cardiology Centre will have a robust internal database for congenital cardiac practice with seamless links to that of the Specialist Children's Surgical Centre.

Within 1 year:

- F1: Each Local Children's Cardiology Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.
- F2: All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes:
  - a. regular continuous network clinical audit and quality improvement;
  - b. regular meetings of the wider network clinical team (in which network patient representatives will be invited to participate) held at least every six months to discuss patient care pathways, guidelines and protocols, review of audit data and monitoring of performance;
  - c. regular meetings of the wider network clinical team, held at least every six months, whose role extends to reflecting on mortality, morbidity and adverse incidents and resultant action plans from all units.
  - Each Local Children's Cardiology Centre will contribute to the network-wide database by diagnosis to support workload planning.

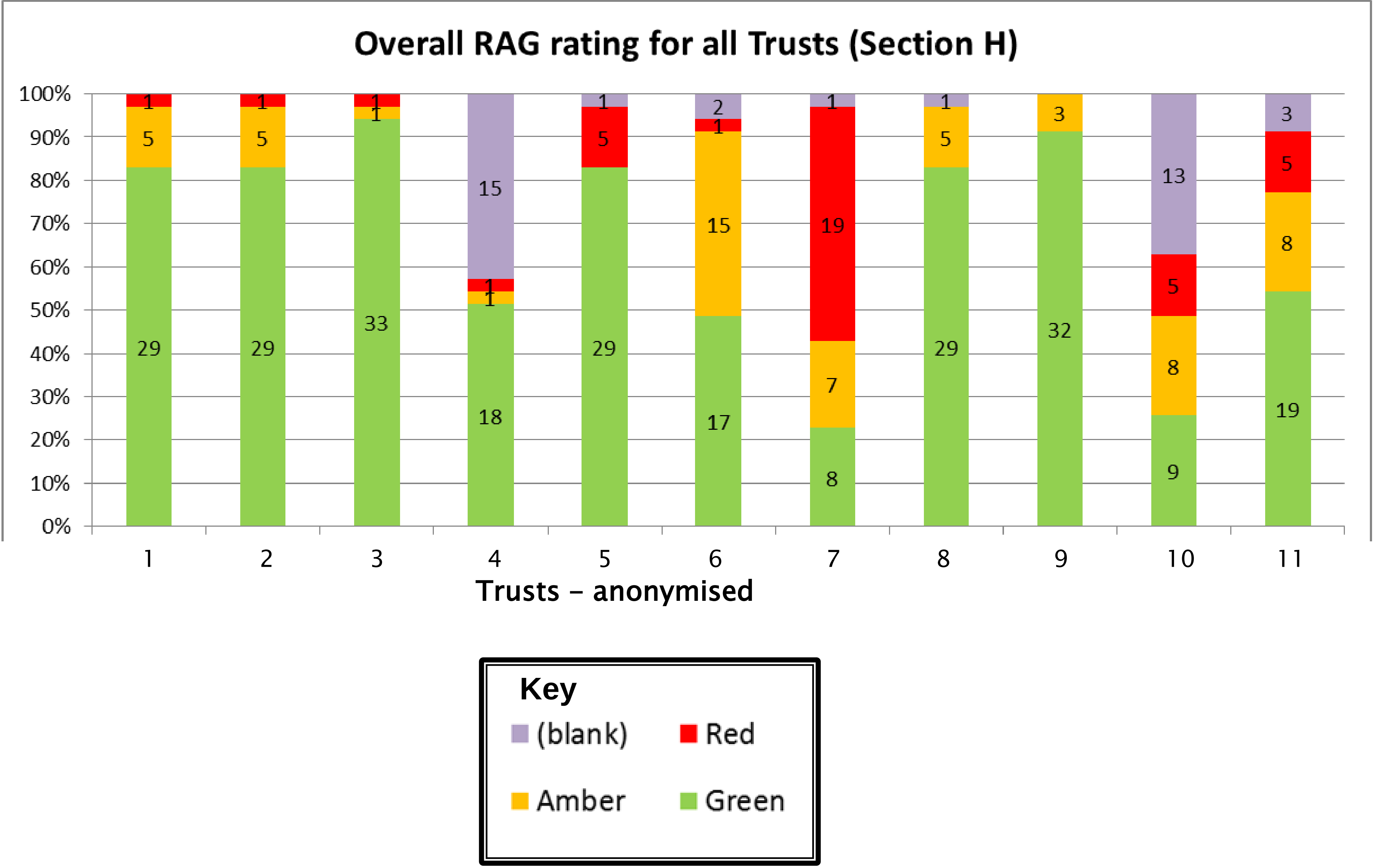


Overall RAG rating for all Trusts (Section G)

Section G – Research

Immediate:

- G1: Each Local Children’s Cardiology Centre should participate in research.
- G2: Where they wish to do so, patients should be supported to be involved in trials of new technologies, medicines etc.



Overall RAG rating for all Trusts (Section H)
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Trusts – anonymised
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Section H – Communication with patients

- **Immediate**:
- H11: The Children’s Cardiac Nurse Specialist will support parents by explaining the diagnosis and management plan of the child/young person’s condition, and providing psychosocial support to promote parental (and child’s/young person’s) adaptation and adjustment.
- H12: The Children’s Cardiac Nurse Specialist must make appropriate referrals as needed and work closely with the learning disability team to provide information and support to patients with learning disabilities. Support for people with learning disabilities must be provided from an appropriate specialist or agency.
- H3: Children and young people, parents and carers must be helped to understand the patient’s condition, the effect it may have on their health and future life and the treatment that they will receive, including involvement with the palliative care team if appropriate. The psychological, social, cultural and spiritual factors impacting on the child/young person’s, parents’ and carers’ understanding must be considered.
- H20: A Children’s Cardiac Nurse Specialist must be available to support parents and children / young people throughout the consent process. When considering treatment options parents /carers and (and young people where appropriate) need to understand the potential risks as well as benefits, the likely results of treatment and the possible consequences of their decisions so that they are able to give informed consent.
- H22: Parents, patients and carers must be provided with information on how to claim travel expenses and how to access social care benefits and support.
- H4: Information must be made available to parents, carers, children and young people in a wide range of formats and on more than one occasion. It must be clear, understandable, culturally sensitive, evidence-based, developmentally appropriate and take into account special needs as appropriate. When given verbally, information must be precisely documented. Information must be interpreted or transcribed as necessary.
- H5: Local Children’s Cardiology Centres must demonstrate that arrangements are in place for parents/carers, children and young people to be given an agreed, written management plan, in a language they can understand that includes notes of discussions with the clinical team, treatment options agreed and a written record of consents.
- H6: The child/young person’s management plan must be reviewed at each consultation – in all services that comprise the local Congenital Heart Network – to make sure that it continues to be relevant to their particular stage of development.

Section H – Communication with patients (cont)

Immediate:

- H7: Children and young people, their families and carers must be encouraged to provide feedback on the quality of care and their experience of the service. Local Children's Cardiology Centres must make this feedback openly available, to children and young people, families/carers and the general public, together with outcome of relevant local and national audits. Local Children's Cardiology Centres must demonstrate how they take this feedback into account when planning and delivering their services. Children, young people, families and carers must be informed of the action taken following a complaint or suggestion made. Local Children's Cardiology Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.
- H8: Each Local Children's Cardiology Centre must have booking systems that allow for long-term follow-up (up to 5 years). Patients and their parents/carers should be reminded of their appointment two weeks before the date to minimise Was Not Brought (WNB) rates.

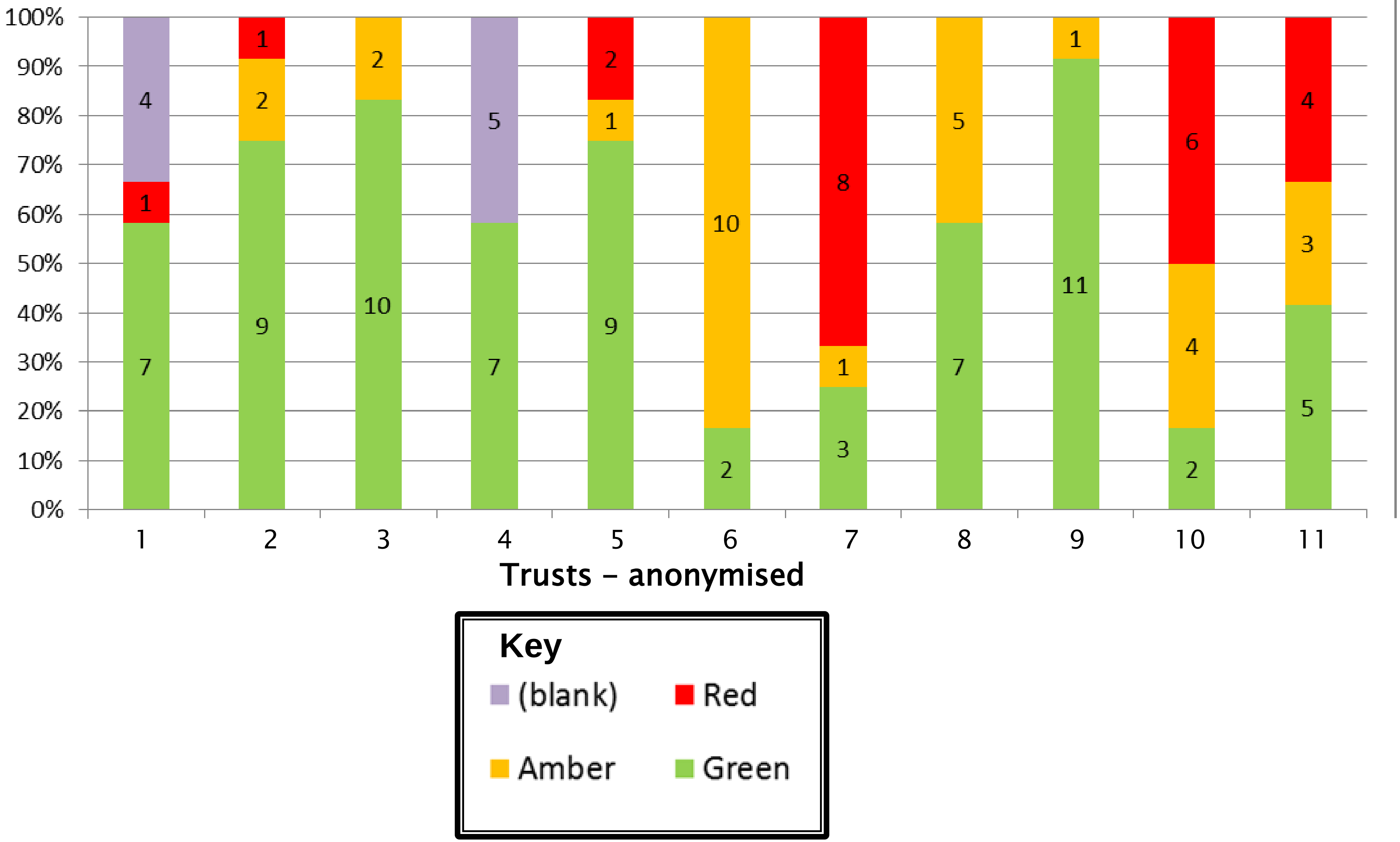
Within 6 months

- H9: Each child/young person must have access to a Children's Cardiac Nurse Specialist (CCNS) who will be responsible for coordinating care across the network, acting as a liaison between the clinical team, the parents/carers and child/young people throughout their care. Children/young people with complex needs must have a named CCNS. CCNS contact details will be given at each attendance at the outpatient clinic.

Within 1 year

- H10: A Children's Cardiac Nurse Specialist must be available at all outpatient appointments to help explain the diagnosis and management of the child/young person's condition and to provide relevant literature.
- H23: A Practitioner Psychologist experienced in the care of paediatric cardiac patients must be available to support families/carers and children/young people at any stage in their care but particularly at the stage of diagnosis, decision-making around care and lifecycle transitions, including transition to adult care. Where this service is not available locally the patient should be referred to the Specialist Surgical Centre or Specialist Children's Cardiology Centre.

Overall RAG rating for all Trusts (Section I)

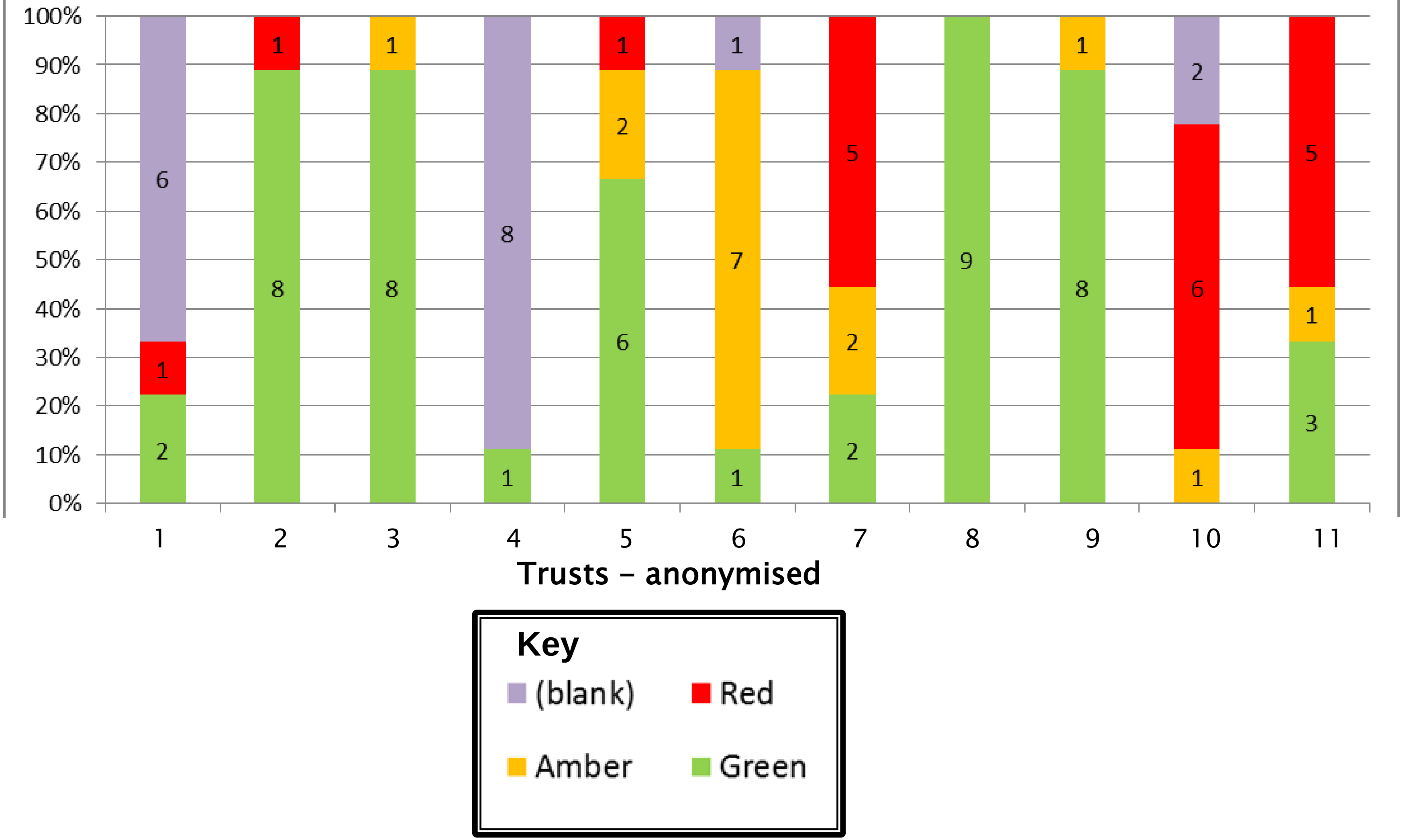


Section I – Transition

Immediate:

- I10: Young people undergoing transition must be supported by age-appropriate information and lifestyle advice. Their attention must be drawn to sources of information and support groups.
- I11: The particular needs of young people with learning disabilities and their parents/carers must be considered, and reflected in an individual tailored transition plan.
- I2: Children and young people should be made aware and responsible for their condition from an appropriate developmental age, taking into account special needs.
- I3: All services that comprise the local Congenital Heart Network must have appropriate arrangements in place to ensure a seamless pathway of care, led jointly by paediatric and adult congenital cardiologists. There must be access to beds and other facilities for adolescents.
- I4: There will not be a fixed age of transition from children's to adult services but the process of transition must be initiated no later than 12 years of age, taking into account individual circumstances and special needs. Transfer will normally be completed by age 18.
- I5: All young people requiring long-term congenital care undergoing transition must be seen at least once for consultation by an ACHD cardiologist and an ACHD Specialist Nurse in a specialist multidisciplinary team transfer clinic or equivalent. Clear care plans/transition passports must be agreed for future management in a clearly specified setting, unless the patient's care plan indicates that they do not need long-term follow-up.
- I7: The Children's Cardiac Transition Nurse will work as a core member of the children's Cardiac Team, liaising with young people, their parents/carers, the Children's Cardiac Nurse Specialist, ACHD Specialist Nurse and wider multidisciplinary team to facilitate the effective and timely transition from the children's to adult services.
- I8: All young people will have a named key worker to act as the main point of contact during transition and to provide support to the young person and their family. Peer to peer support should also be offered.
- I9: All patients transferring between services will be accompanied by high quality information, including the transfer of medical records, imaging results and the care plan.
- **Within 1year:**
- I1: Congenital Heart Networks must demonstrate arrangements to minimise loss of patients to follow-up during transition and transfer. The transition to adult services will be tailored to reflect individual circumstances, taking into account any special needs.
- I12: Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to parents/family or carers.

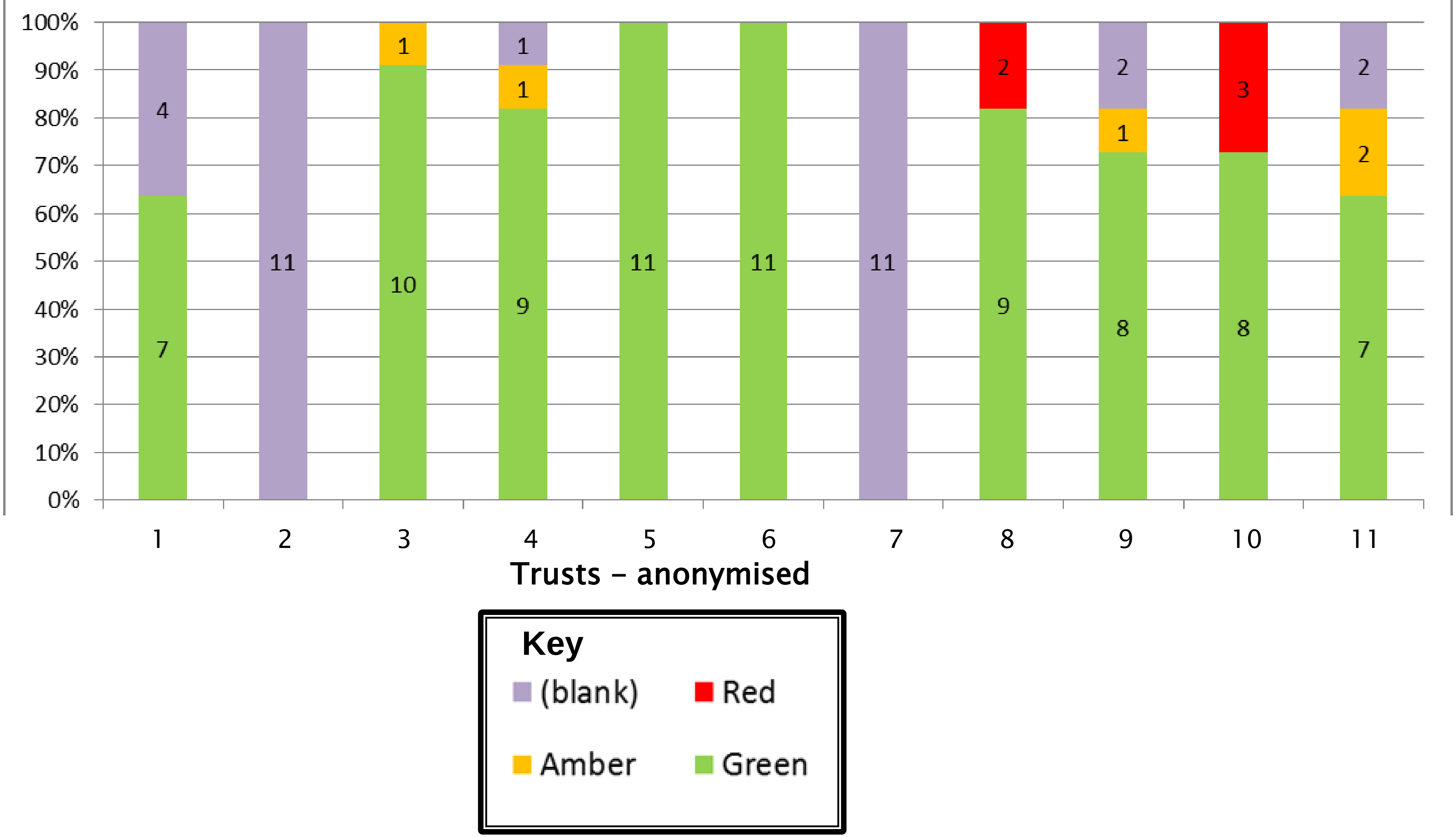
Overall RAG rating for all Trusts (Section J)



Section J – Pregnancy & Contraception

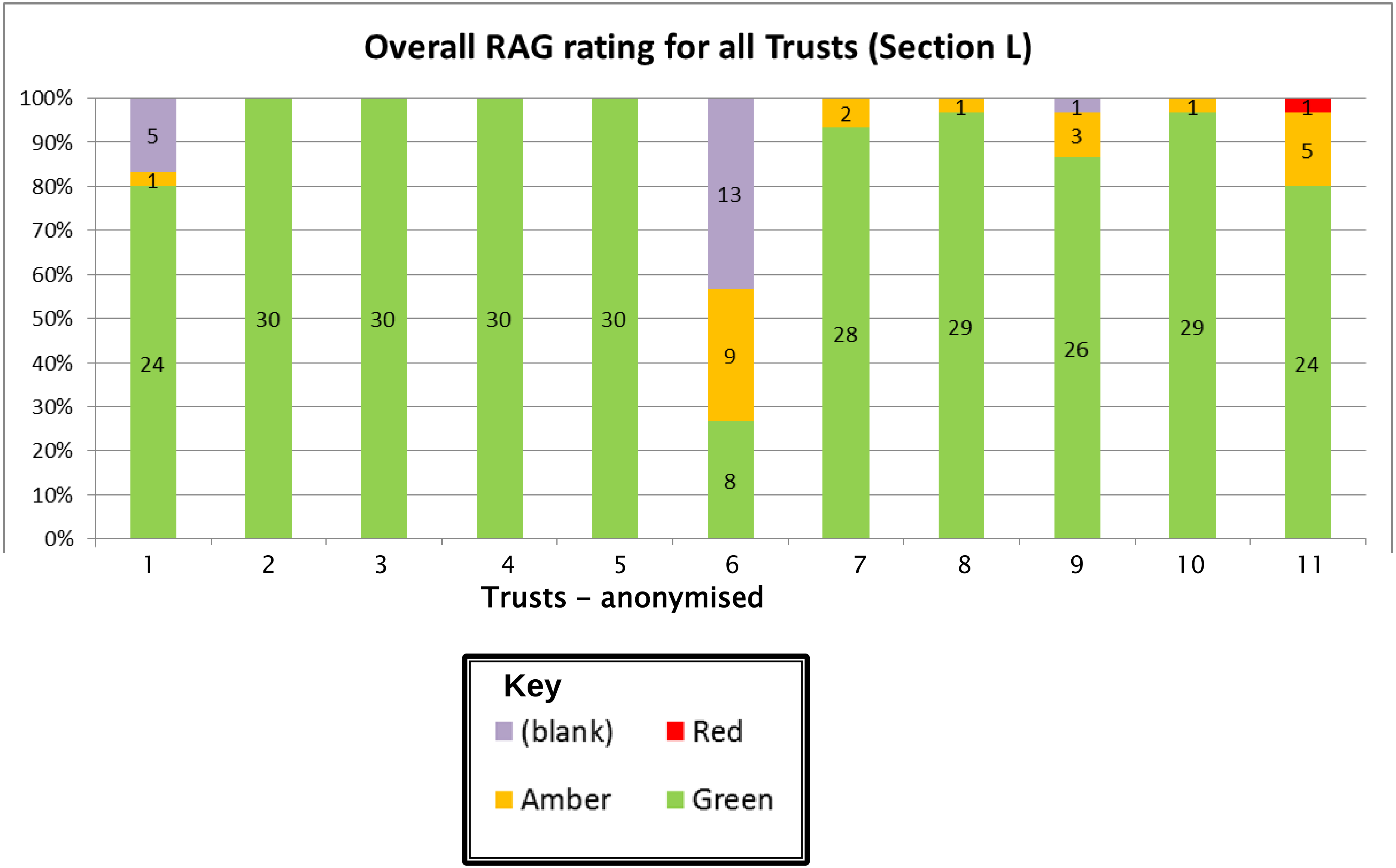
- **Immediate**:
- J1: All female patients of childbearing age must be given an appropriate opportunity to discuss their childbearing potential with a consultant paediatric cardiologist or paediatrician with expertise in cardiology and a nurse specialist with expertise in pregnancy in congenital heart disease. Where this is not provided in the Local Children's Cardiology Centre, the patient must be offered access to the service through an outreach clinic, at the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre.
- J2: Discussions should begin during transition, introduced in the paediatric setting as appropriate to age, culture, developmental level and cognitive ability and taking into account any personal/cultural expectations for the future.
- J2: In line with national curriculum requirements, from age 12, female patients will have access to specialist advice on contraception and childbearing potential and counselling by practitioners with expertise in congenital heart disease.
- J2: The principle of planned future pregnancy, as opposed to unplanned and untimely pregnancy, should be supported.
- J2: Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided as appropriate, in preparation for when this becomes relevant to them. They must have ready access to appropriate contraception, emergency contraception and termination of pregnancy.
- J4: All male patients must have access to counselling and information about contraception and recurrence risk by a consultant paediatric cardiologist or paediatrician with expertise in cardiology and nurse specialist with expertise in congenital heart disease and, where appropriate, by a consultant geneticist.
- J4: Where this is not provided in the Local Children's Cardiology Centre, the patient must be offered access to the service through an outreach clinic at the Specialist Children's Surgical Centre or Specialist Children's Cardiology Centre.
- J5: Patients must be offered access to a Practitioner Psychologist, as appropriate, throughout family planning and pregnancy and when there are difficulties with decision-making, coping or the patient and their partner are concerned about attachment.

Overall RAG rating for all Trusts (Section K)



Section K – foetal diagnosis

- **Immediate:**
- K5: A Fetal Cardiac Nurse Specialist will be present during the consultation or will contact all prospective parents whose baby has been given an antenatal diagnosis of cardiac disease to provide information and support on the day of diagnosis. Parents must
- K5: The Fetal Cardiac Nurse Specialist (FCNS) must work in collaboration with the Cardiologist and fetal medicine team to ensure that condition-specific information, explanation of treatment options, and psychosocial support is provided. The FCNS will act as the point of contact for the family throughout pregnancy for support and further information.

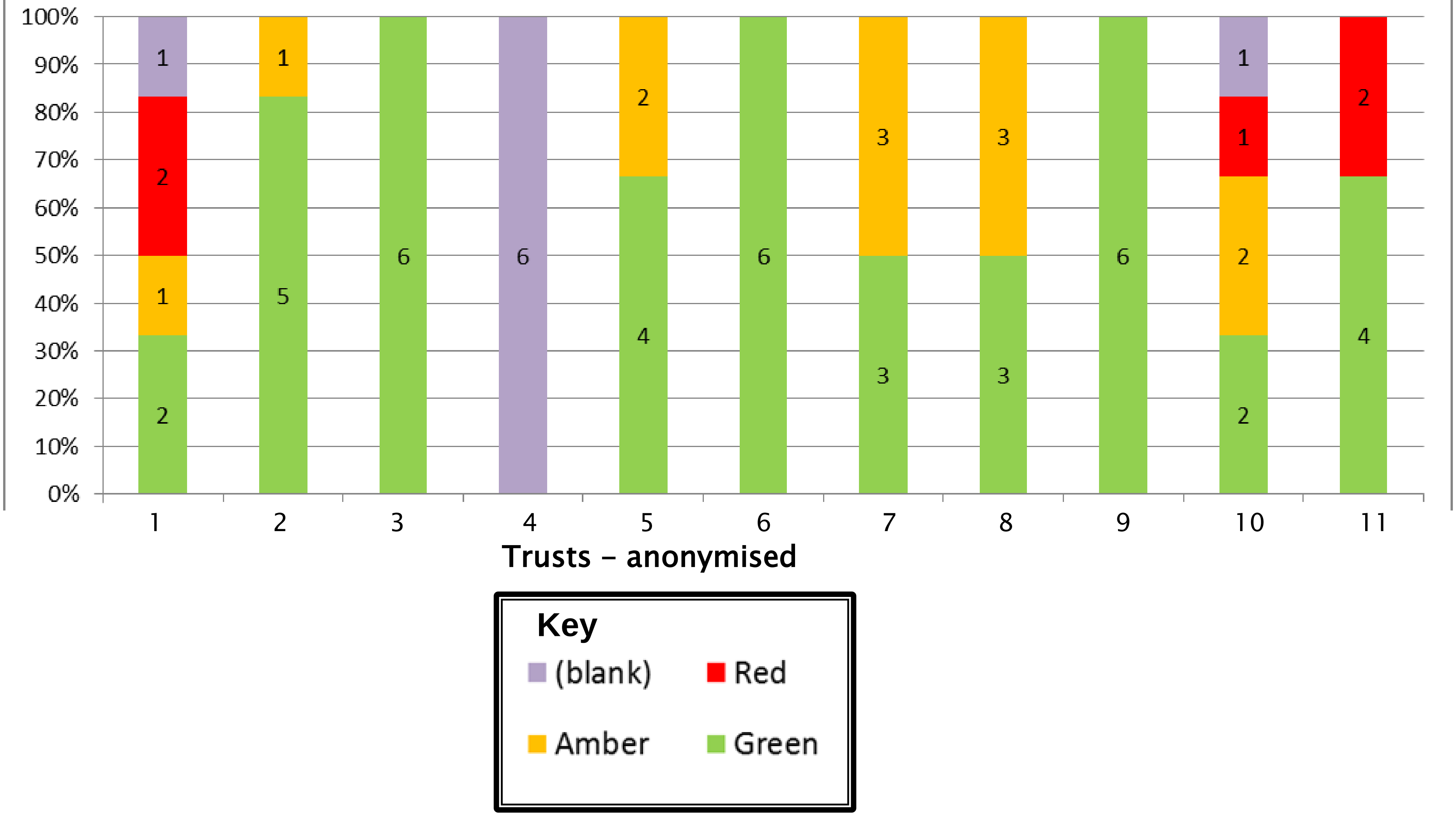


Overall RAG rating for all Trusts (Section L)

Section L – palliative care and bereavement

- **Immediate:**
- L3: Each Local Children's Cardiology Centre must provide access to a palliative care service able to provide good quality end-of-life care in hospital and with well-developed shared-care palliative services in the community which are appropriate to the physical, psychological, cognitive and cultural needs of the child/young person and family/carers. This must also include bereavement follow-up and referral on for ongoing emotional support of the family/carers.
- L2: Clinicians should use nationally approved paediatric palliative medicine guidance to plan palliative care from the point of diagnosis.

Overall RAG rating for all Trusts (Section M)



Section M – Dental

- **Immediate:**
- M2: Each Local Children’s Cardiology Centre must ensure that identified dental treatment needs are addressed prior to referral (where possible) and any outstanding treatment needs are shared with the interventional/surgical team and included in referral documentation.
- M3: All children at increased risk of endocarditis must be referred for specialist dental assessment at two years of age, and have a tailored programme for specialist follow-up.
- M4: Each Congenital Heart Network must have a clear referral pathway for urgent dental assessments for congenital heart disease patients presenting with infective endocarditis, dental pain, acute dental infection or dental trauma. All children and young people admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.

How do we address the gaps

- What approaches do we need for each of the areas (for example):
  - Peer sharing of best practice from centres that are green
  - Guidance from level 1 / network team
  - Working group to develop guidance / approach
  - Commissioner support for investment / escalation to national programme board for prioritisation
  - Patient group to inform approach / priorities
  - etc.