Congenital Heart Disease Network – South Wales and South West

Analysis of self-assessment against the new CHD Standards

Adult Level 3 Centres

September 2016

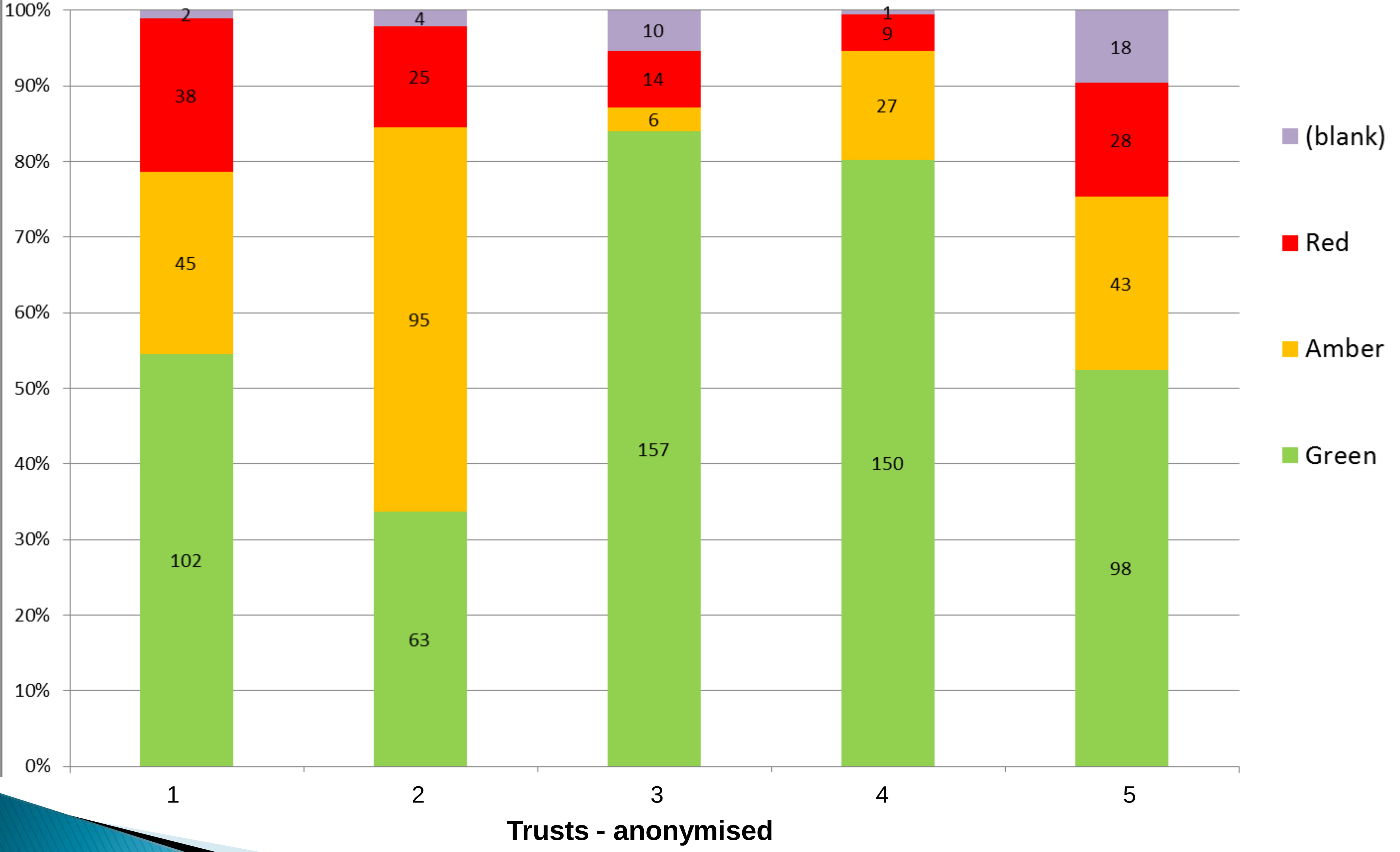
Response rate and overview

- 5 of 12 level 3 adult's centres completed the self assessment: Royal Cornwall are due to complete in the next 2 weeks, other centres TBC
- Across the 5 Trusts, 570 (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

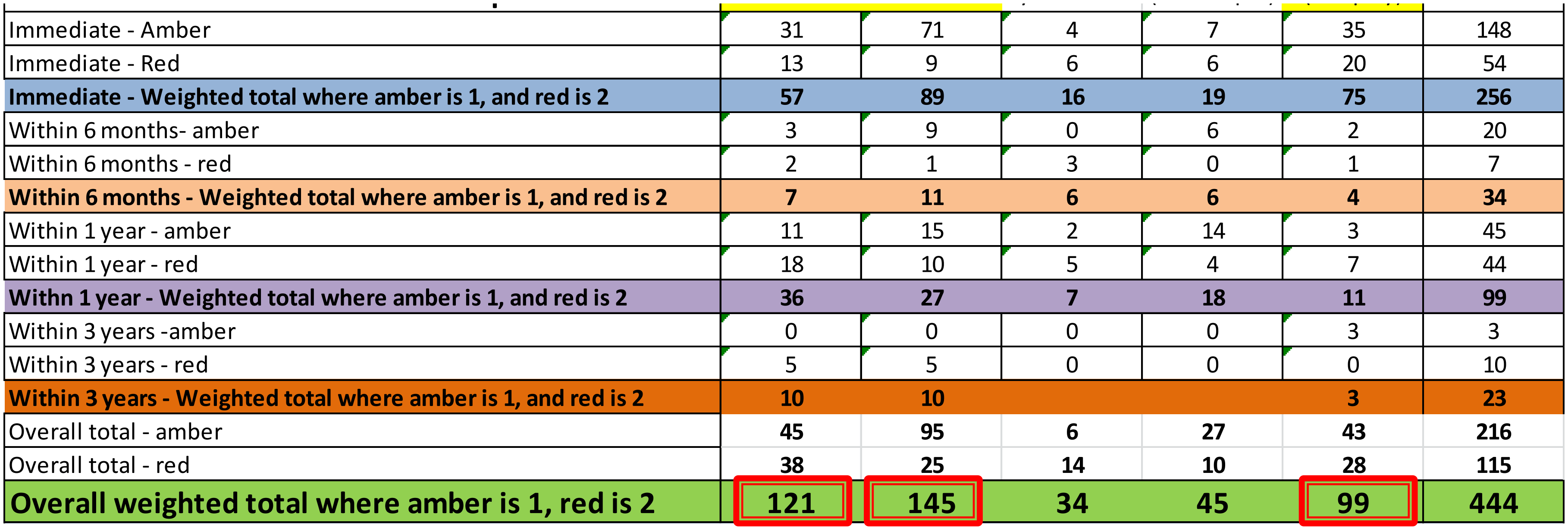
Method to identify themes to be addressed

- 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)



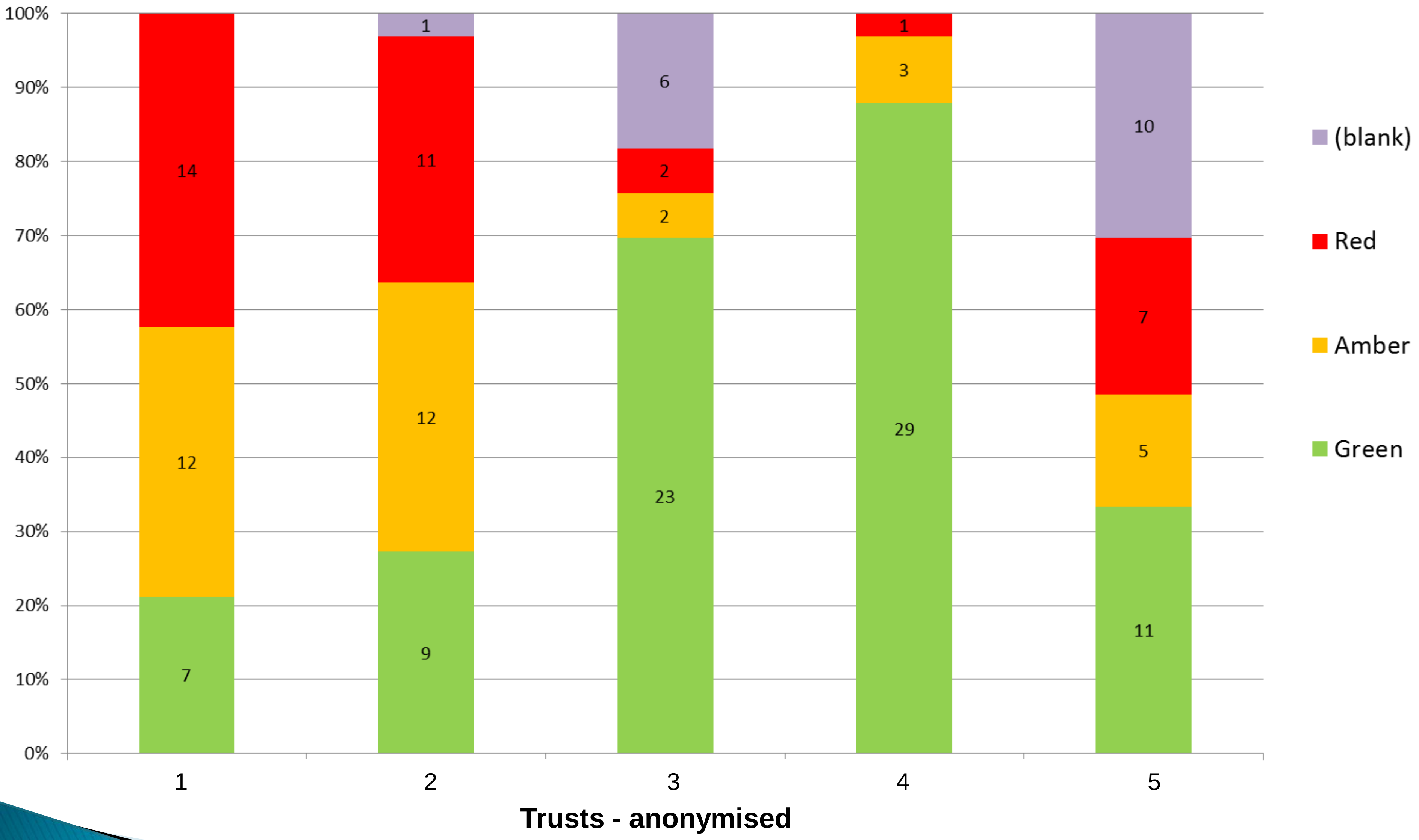
All Trusts Overview



Immediate - Amber	31	71	4	7	35	148
Immediate - Red	13	9	6	6	20	54
Immediate - Weighted total where amber is 1, and red is 2	**57**	**89**	**16**	**19**	**75**	**256**
Within 6 months- amber	3	9	0	6	2	20
Within 6 months - red	2	1	3	0	1	7
Within 6 months - Weighted total where amber is 1, and red is 2	**7**	**11**	**6**	**6**	**4**	**34**
Within 1 year - amber	11	15	2	14	3	45
Within 1 year - red	18	10	5	4	7	44
Withn 1 year - Weighted total where amber is 1, and red is 2	**36**	**27**	**7**	**18**	**11**	**99**
Within 3 years -amber	0	0	0	0	3	3
Within 3 years - red	5	5	0	0	0	10
Within 3 years - Weighted total where amber is 1, and red is 2	**10**	**10**			**3**	**23**
Overall total - amber	**45**	**95**	**6**	**27**	**43**	**216**
Overall total - red	**38**	**25**	**14**	**10**	**28**	**115**
Overall weighted total where amber is 1, red is 2	**121**	**145**	**34**	**45**	**99**	**444**

- 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)



Section A – Network Approach Key Gaps

Immediate:

- A14: Staff from across the Local ACHD Centre should be encouraged to attend multidisciplinary (MDT) meetings in person or by video/teleconferencing and participate in the decision-making about their patient, where necessary.
- A3: Local ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care for:
  - a. New referrals from GPs, cardiologists and local hospitals
  - b. Ongoing care of patients diagnosed with congenital heart defects
- A7: Local ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will require all ACHD surgery, including atrial septal defect closure, therapeutic interventions and diagnostic catheter procedures to take place within a Specialist ACHD Surgical Centre.
- A8: Local ACHD Centres will agree with their Congenital Heart Network clinical protocols and pathways to care that will ensure the availability of a pre-operative risk assessment for patients requiring non-cardiac surgery by an ACHD specialist, and other specialist advice, including a decision on the most appropriate location for that surgery.
- A9: When patients with CHD attend A&E or are admitted, whether for CHD-related problems or not, Local ACHD Centres will seek advice from the local cardiologist with expertise in CHD or an ACHD cardiologist at a specialist centre on appropriate care and management.

Within 6 months:

- A13: Each Local ACHD Centre must cooperate to allow specialist consultants doing outreach clinics and multidisciplinary team meetings to gain remote access to their own Specialist ACHD Surgical Centre or Specialist ACHD Centre system and enable immediate access to patient data.
- A2: Each Local ACHD Centre will provide appropriate managerial and administrative support for the effective operation of the network.
- A5: There will be specific protocols within each Congenital Heart Network for the transfer of patients requiring interventional treatment.

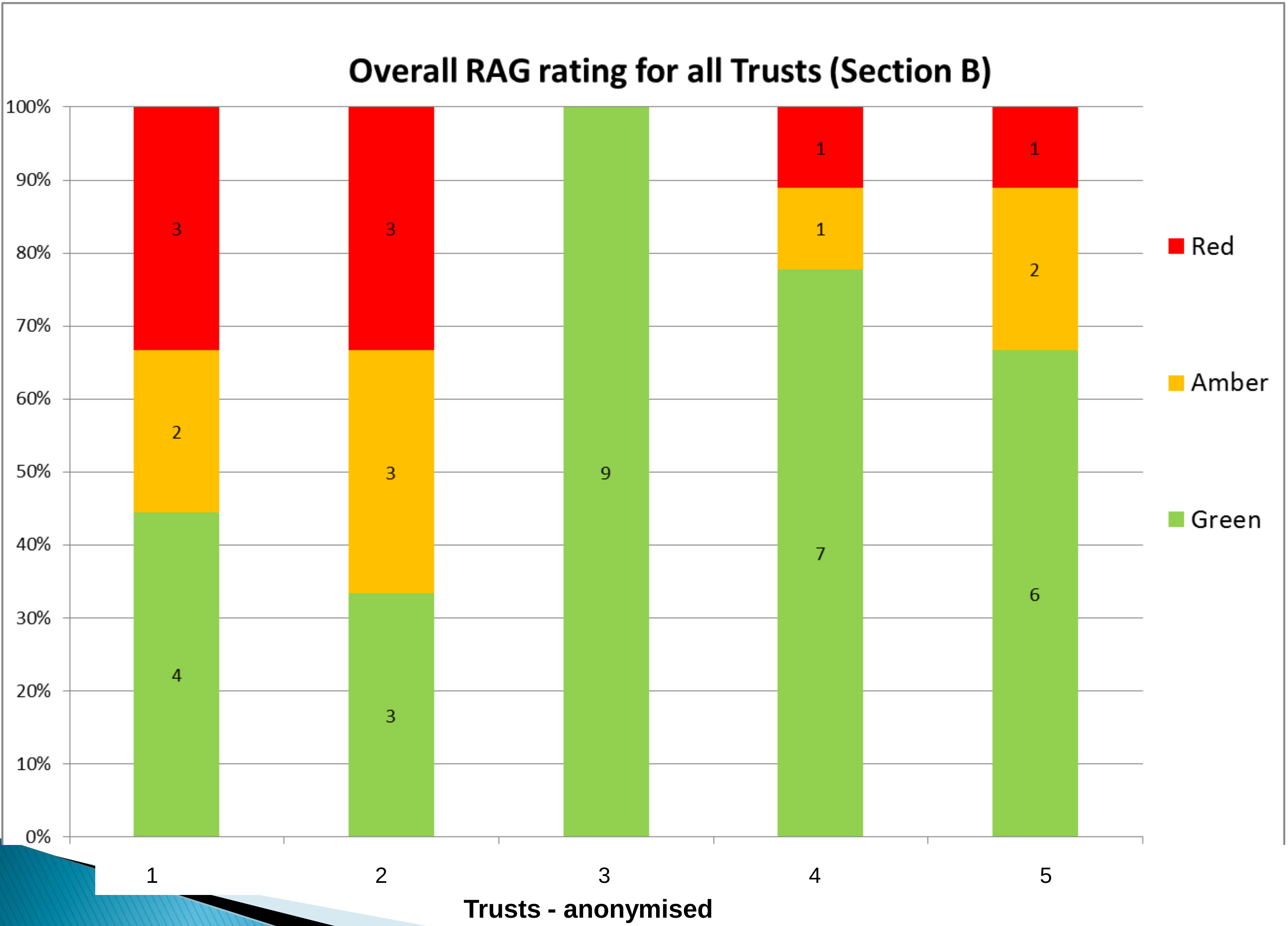
Section A – Network Approach (cont)

Within 1 year

- A15: Each Local ACHD Centre cardiologist with an interest in ACHD must participate (at least six times per year) in specialist MDT meetings led by the Specialist ACHD Surgical Centre, either in person or via telemedicine facilities, and must also attend the annual network meeting. This requirement will be reflected in job plans.
- A17: Each Local ACHD Centre must have identified registered nurses with an interest and training in ACHD.
- A4: Local ACHD Centres will adhere to their Congenital Heart Network's clinical protocols and pathways to care that will:
  - c. have a clear pathway for managing patients who self-refer out of hours, ideally using the patient passport or other equivalent electronic care record, and with clear links to 24/7 specialist services;
  - f. address how Local ACHD Centres will communicate effectively with colleagues across the Congenital Heart Network on the care of patients requiring non-cardiac interventions;
  - Local ACHD Centres will provide weekday cover for CHD advice from a local network of consultant cardiologists with expertise in CHD.

Within 3 years:

- A12: Each Local ACHD Centre will have telemedicine facilities as required to link with designated hospitals in the network (Specialist ACHD Surgical Centres and Specialist ACHD Centres, according to local circumstances). The level of telemedicine required will be agreed between network members. As a minimum this must include the facility to:
  - a. undertake initial assessments of echocardiograms;
  - b. support participation in multi-site VC multidisciplinary team meetings;
  - c. handle emergency referrals;


Overall RAG rating for all Trusts (Section B)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
3
2
4
3
3
3
9
1
1
7
1
2
6
Red
Amber
Green
1
2
3
4
5
Trusts - anonymised

Section B – Staffing & Skills

Immediate:

- B4: ACHD Specialist Nurses from the Specialist ACHD Surgical Centre or Specialist ACHD Centre will provide support, education and a link to the outpatient and ward nursing staff at Local ACHD Centres. A local link nurse will be identified who can be a point of contact within the Local ACHD Centre.

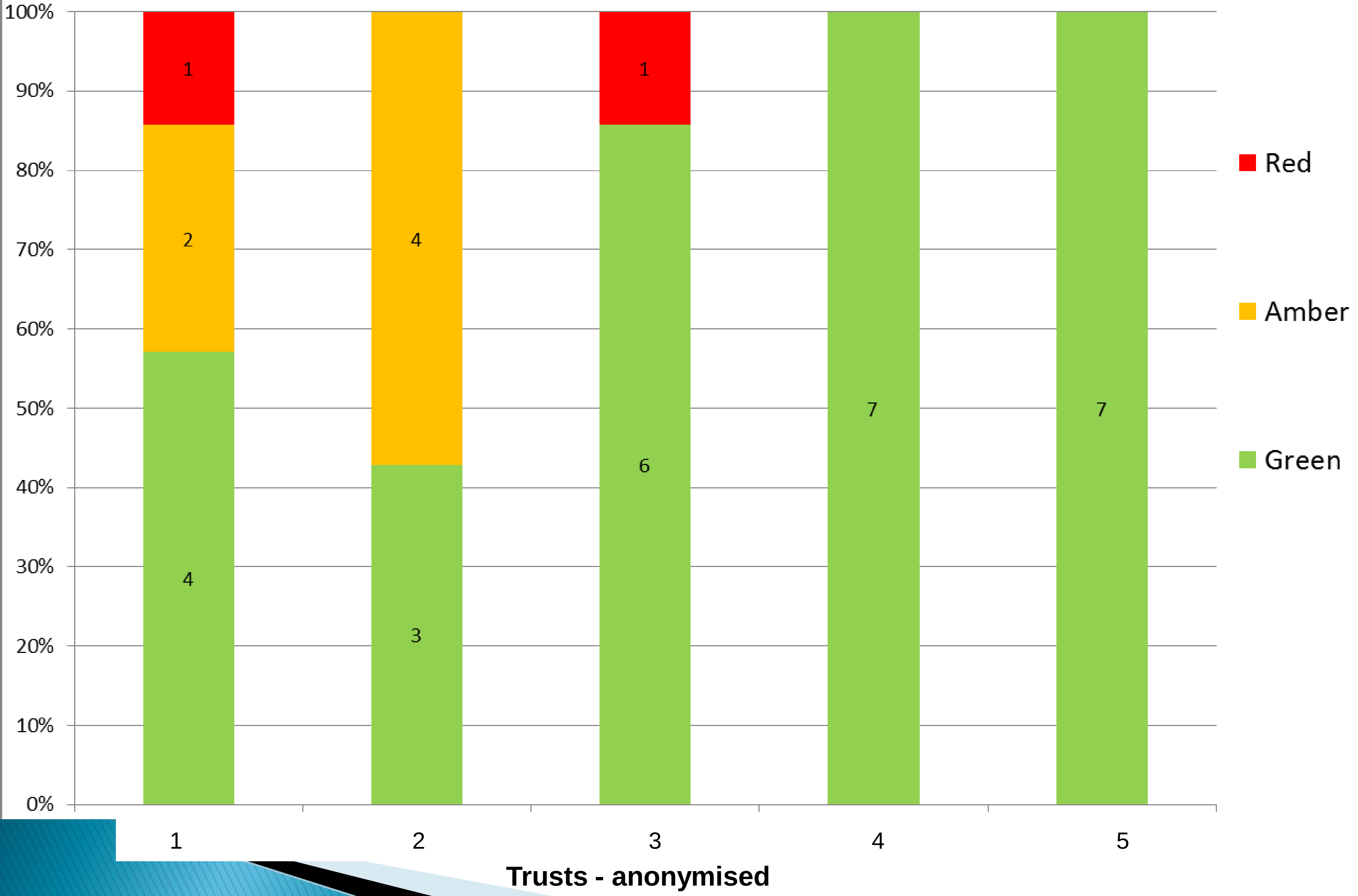
Within 6 months

- B5: Each Local ACHD Centre must have an identified member of staff to ensure high quality data input to the network database.

Within 1 year:

- B3: Each Local ACHD Centre must have a locally designated 0.25 WTE registered nurse with a specialist interest to participate in ACHD clinics, provide support to inpatients and deal with requests for telephone advice.
- B7: Each Local ACHD Centre must have a cardiac physiologist with training in congenital echocardiography.

Overall RAG rating for all Trusts (Section C)

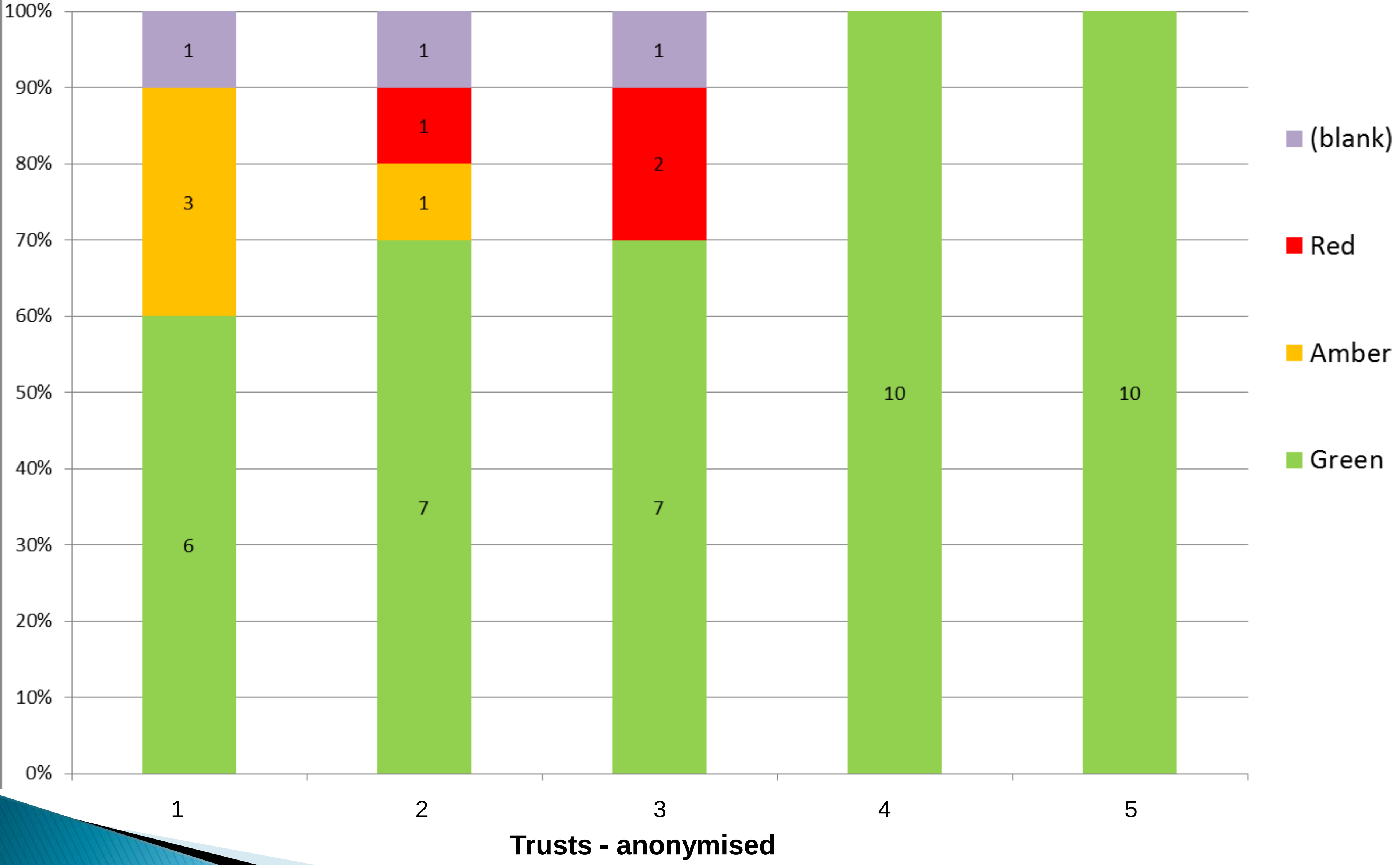


Section C – Facilities

Immediate:

- C5: Patients and their partners/family/carers must be provided with accessible information about the service and the hospital, including information about amenities in the local area, travelling, parking and public transport.
- C7: All patients should have access to cardiac rehabilitation facilities.

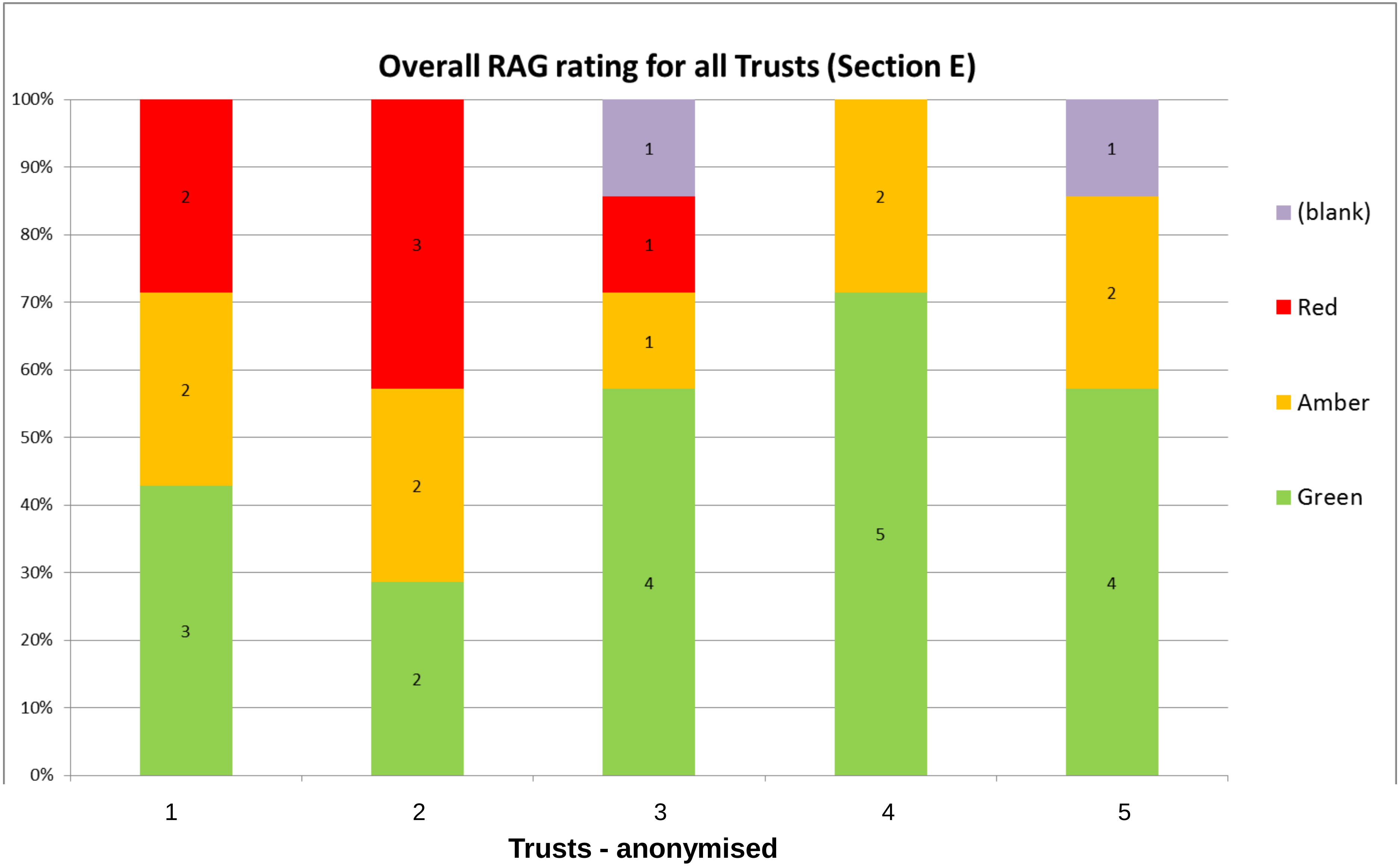
Overall RAG rating for all Trusts (Section D)



Section D – Interdependencies

Immediate:

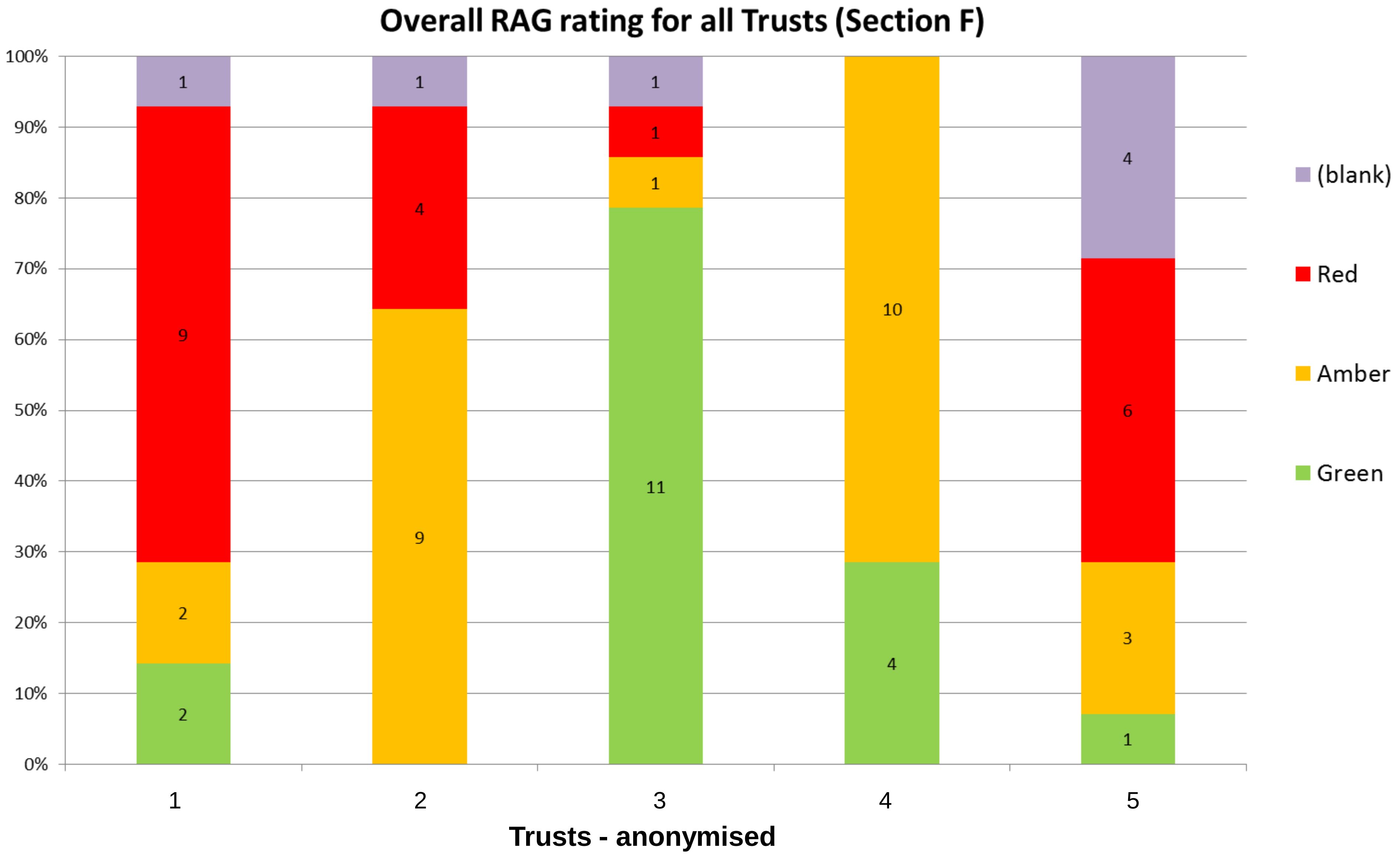
- D1: The following specialties or facilities must be located on the same hospital site as Local ACHD Centres.: General adult cardiology services, including acute cardiac care unit.
- D3: Each Local ACHD Centre must be appropriately staffed to undertake the following investigations: e. exercise testing/six-minute walk test;


Overall RAG rating for all Trusts (Section E)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
2
2
3
3
2
2
1
1
1
4
2
5
1
2
4
(blank)
Red
Amber
Green
1
2
3
4
5
Trusts - anonymised

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 patients and their partners, families and carers through loss. Identified members of the medical and nursing team will need to undergo further in-depth training.
- E3: Each Local ACHD Centre must assist the Specialist ACHD Surgical Centre in providing core curriculum level training as per the Joint Royal Colleges of Physicians' Training Board curriculum to all adult cardiology trainees within their network catchment area.
- 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 patients with congenital heart problems.
- E5: Each Local ACHD Centre must have one individual who is responsible for ensuring continuing professional development for all staff delivering ACHD care at the Local ACHD Centre. This individual will work with those at the Specialist ACHD Surgical Centre to deliver standardised training and competency-based education programmes across the Congenital Heart Network. 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 ACHD Centres must be offered allocated rotational time working in the Specialist ACHD Surgical Centre or Specialist ACHD Centre, to enhance development of clinical knowledge and skills enabling professional development and career progression. A formal annual training plan should be in place.


Overall RAG rating for all Trusts (Section F)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
1
9
2
2
1
4
9
1
1
1
11
10
4
4
6
3
1
(blank)
Red
Amber
Green
1
2
3
4
5
Trusts - anonymised

Section F – Organisation

Immediate:

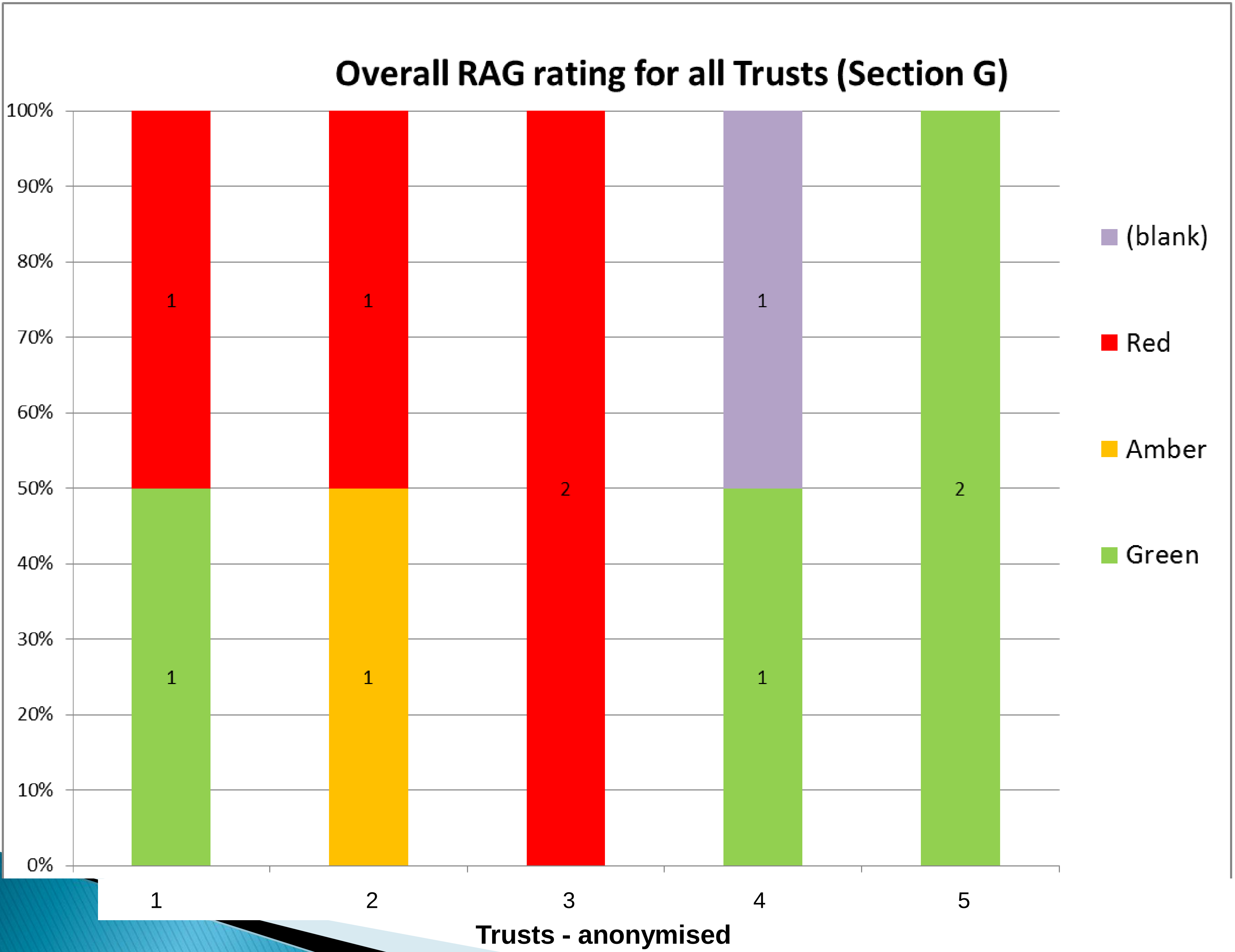
- F10: Where cases are referred to the specialist multidisciplinary team meeting for a decision on management, they must be considered and responded to within a maximum of six weeks and according to clinical urgency.
- F3: Each Local ACHD Centre will report on adverse incidents. In addition to contractual and national reporting requirements, Local ACHD Centres must demonstrate how details of adverse incidents are disseminated locally and nationally across the Congenital Heart Networks.
- F5: Each Local ACHD 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 ACHD Centre must participate in relevant national programmes for audit and must submit data to the Specialist ACHD Surgical or Specialist ACHD 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 ACHD Centre must work with the network to discuss, plan and manage the introduction of new technologies and treatments with NHS commissioners. Local ACHD Centres will follow mandatory National Institute for Health and Care Excellence guidance.

Within 6 months

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

Within 1 year

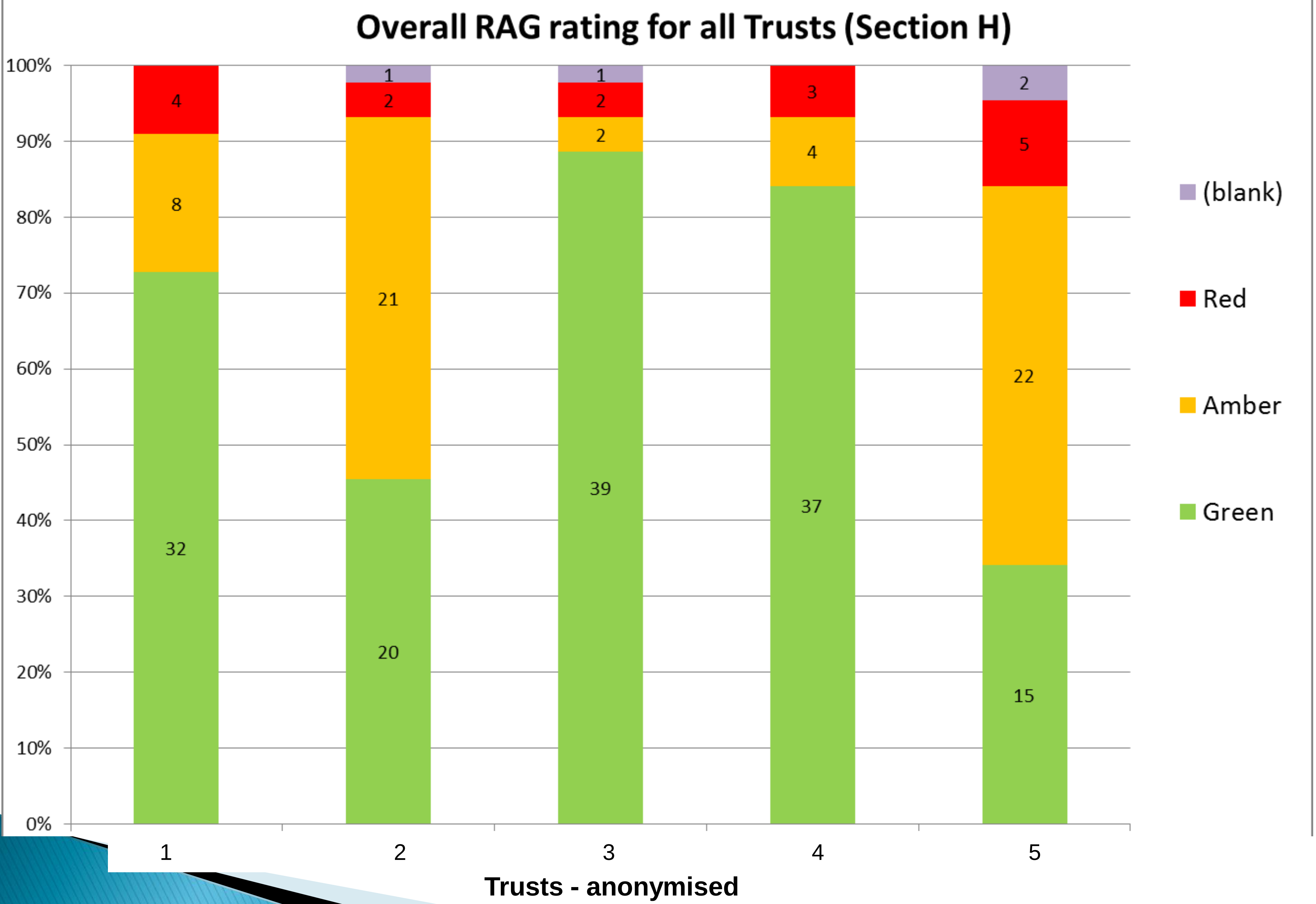
- F1: Each Local ACHD Centre must demonstrate a robust policy for collaboration with each other and with NHS commissioners for audit, including formal inter-unit peer review every five years.
- F2: All clinical teams within the Congenital Heart Network will operate within a robust and documented clinical governance framework that includes:
  - a. regular continuous network clinical audit and quality improvement;
  - 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.
- F8: Each Local ACHD Centre will contribute to the network-wide database by diagnosis to support workload planning.


Overall RAG rating for all Trusts (Section G)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
1
1
1
1
2
1
1
2
1
2
3
4
5
Trusts - anonymised
(blank)
Red
Amber
Green

Section G – Research

Immediate:

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


Overall RAG rating for all Trusts (Section H)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
4
8
32
1
2
21
20
1
2
2
39
3
4
37
2
5
22
15
(blank)
Red
Amber
Green
1
2
3
4
5
Trusts - anonymised

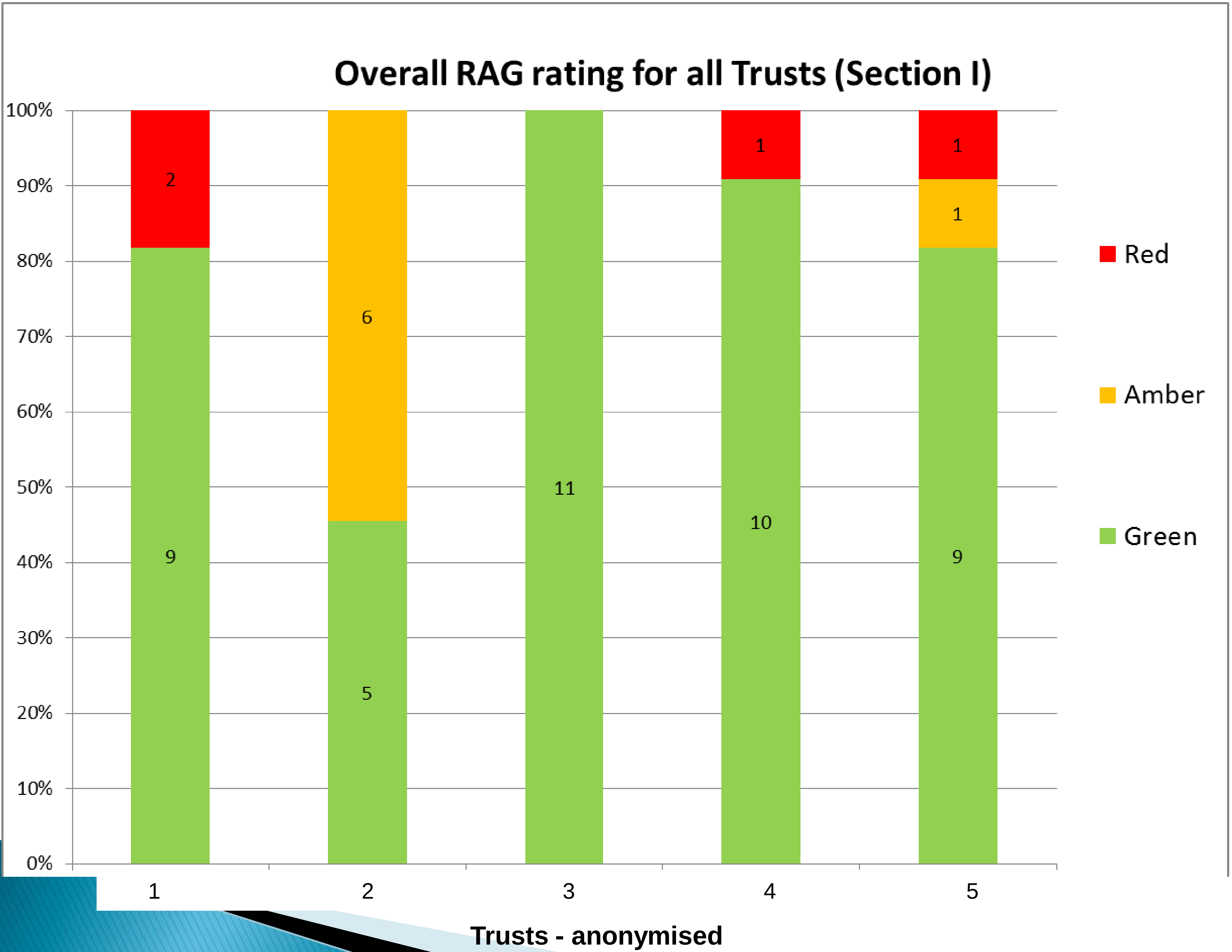
Section H – Communication with patients

Immediate:

- H15: Copies of all correspondence for GP and local centres must be copied to the patient in plain language to retain in the patient's personal record in accordance with national guidance.
- H17: Partners/family/carers should be offered resuscitation training when appropriate.
- H18: Local ACHD Centres must demonstrate that patients and carers must be offered support or cooperation in obtaining further opinions or referral to another centre, and in interpreting publicly available ACHD data that supports patient choice.
- H19: Where surgery or intervention is planned, Local ACHD Centres must ensure that the patient and their partner, family or carers have the opportunity to visit the Specialist ACHD Surgical Centre in advance of admission (as early as possible) to meet the team that will be responsible for their care. This must include the opportunity to meet the surgeon or interventionist who will be undertaking the procedure.
- H2: Every patient must be given a detailed written care plan forming a patient care record, in plain language, identifying the follow-up process and setting. The plan must be copied to all involved clinicians and the patient's GP.
- H22: Patients must be provided with information on how to claim travel expenses and how to access social care benefits and support.
- H7: Local ACHD Centres must demonstrate how they take this feedback into account when planning and delivering their services.
- H7: Local ACHD Centres must demonstrate ongoing structured liaison with patients and patient groups, including evidence of how feedback is formally considered.
- H7: Local ACHD Centres must make this feedback openly available to patients, partners/families/carers and the general public, together with outcome of relevant local and national audits.
- H8: Patients should be reminded of their appointment two weeks before the date to minimise Did Not Attend (DNA) rates.

Within 1 year

- H23: A Practitioner Psychologist experienced in the care of congenital cardiac patients must be available to support patients 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 ACHD Surgical Centre or Specialist ACHD Centre.


Overall RAG rating for all Trusts (Section I)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
2
9
6
5
11
1
10
1
1
9
1
2
3
4
5
Trusts - anonymised
🟥 Red
🟧 Amber
🟩 Green

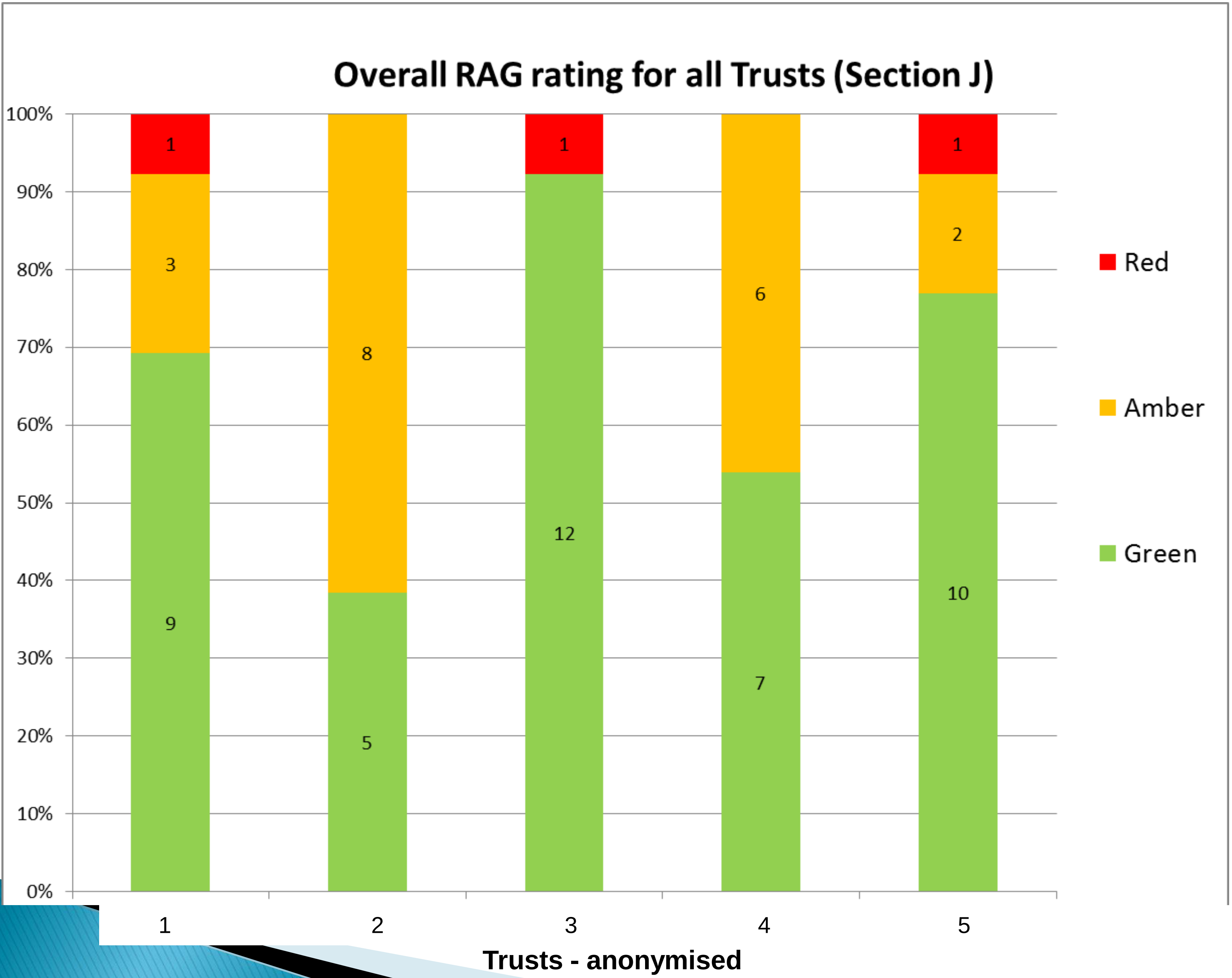
Section I – Transition

Immediate:

- I1: ‘Lost to follow-up’ rates must be recorded and discussed at the network multidisciplinary team meeting.

Within 1 year:

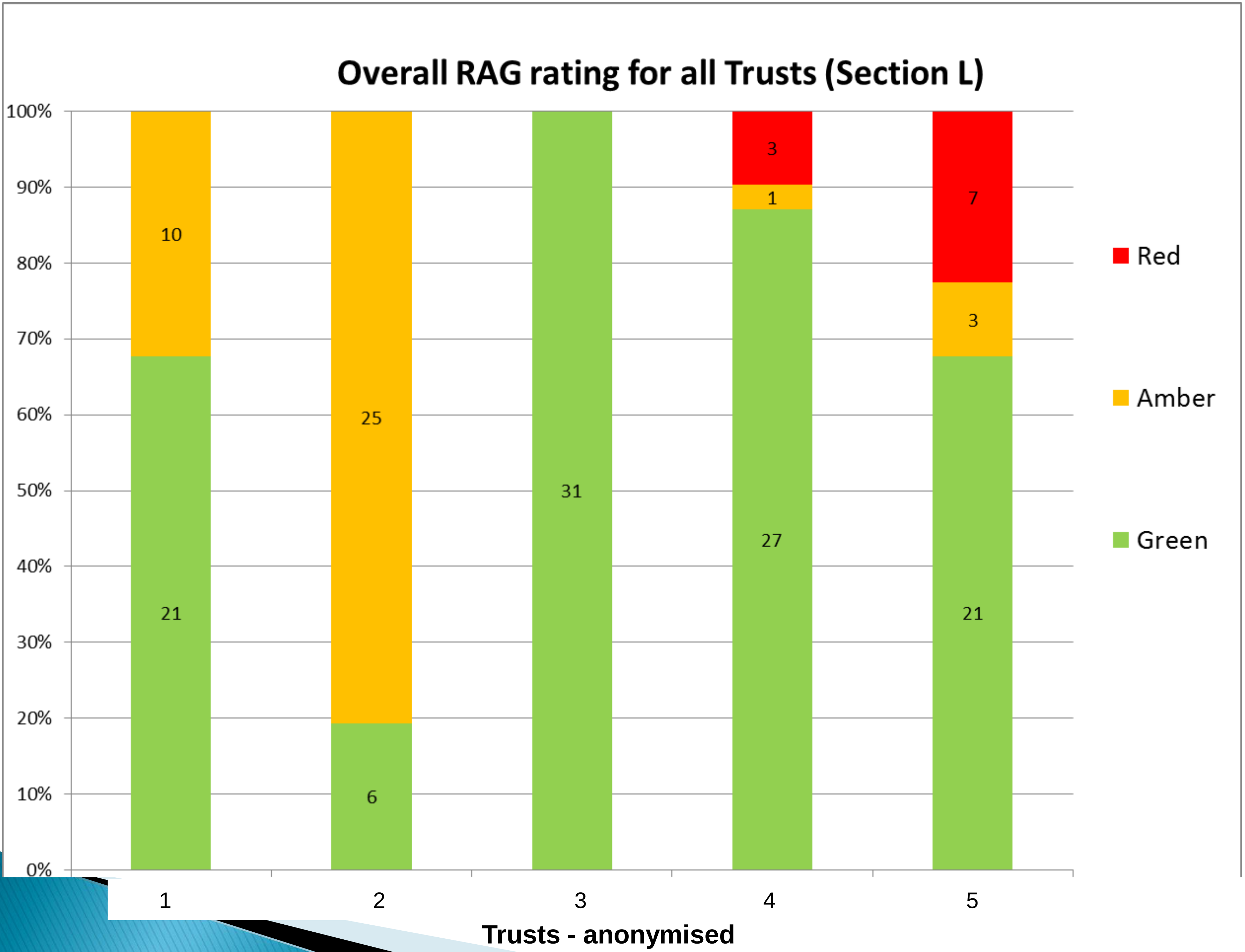
- I9: Young people must have the opportunity to be seen by a Practitioner Psychologist on their own. Psychological support must also be offered to partners/family or carers.


Overall RAG rating for all Trusts (Section J)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
1
3
9
8
5
1
12
6
7
1
2
10
🟥 Red
🟨 Amber
🟩 Green
1
2
3
4
5
Trusts - anonymised

Section J – Pregnancy & Contraception

Immediate:

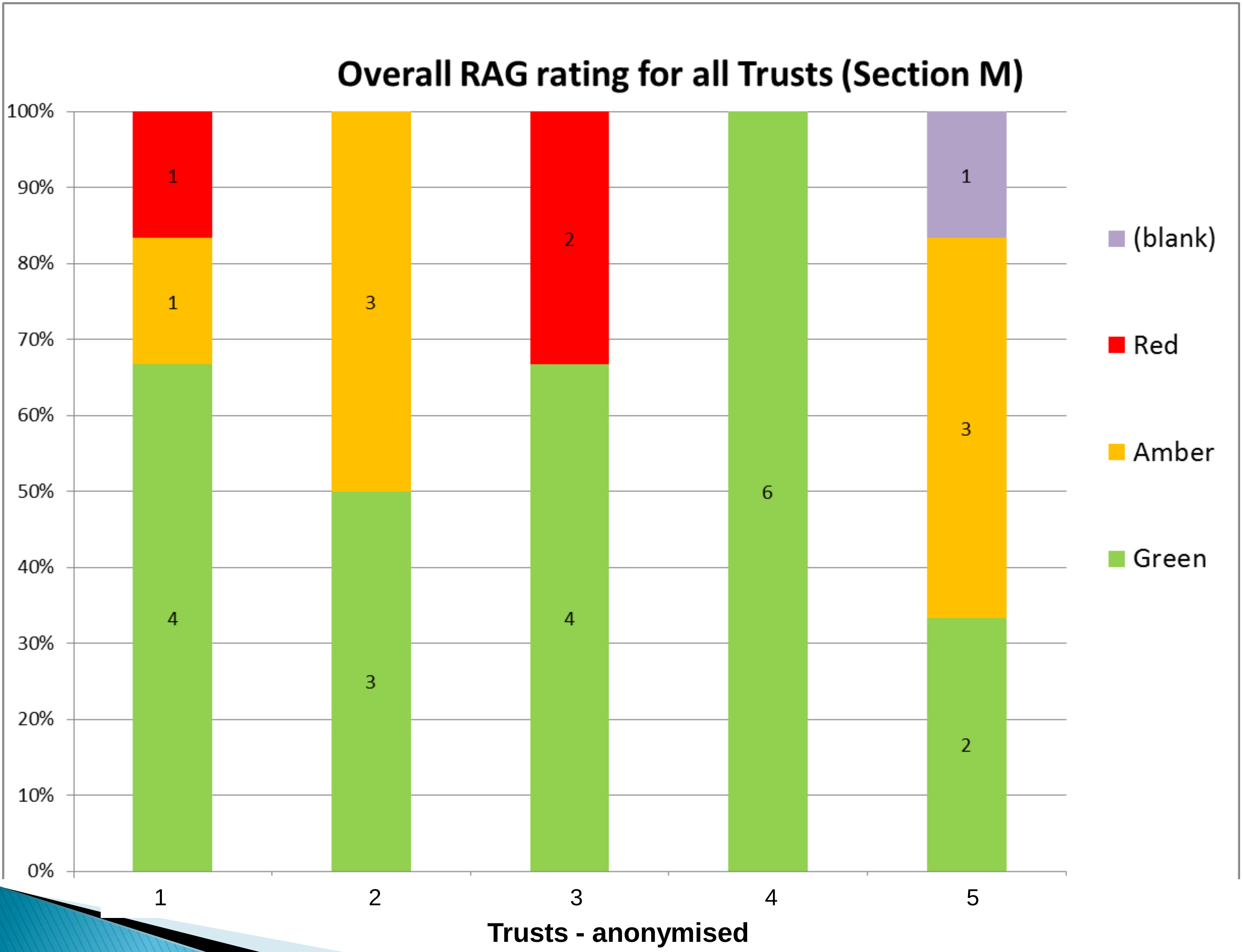
- J2: Written advice about sexual and reproductive health, and safe forms of contraception specific to their condition must be provided. They must have ready access to appropriate contraception, emergency contraception and termination of pregnancy.
- J4: All male patients must have access to counselling and information about contraception and recurrence risk by a consultant ACHD cardiologist and nurse specialist with expertise in congenital heart disease, and, where appropriate, by a consultant geneticist
- 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.
- J6: The plan must be made in conjunction with the obstetric services. This must include access to termination of pregnancy services. The individualised care plan must cover the antenatal, intrapartum and postnatal periods. It must include clear instructions for shared care with secondary services, when appropriate, including escalation and transfer protocols and clear guidelines for planned and emergency delivery.


Overall RAG rating for all Trusts (Section L)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
10
21
25
6
31
3
1
27
7
3
21
Red
Amber
Green
1
2
3
4
5
Trusts - anonymised

Section L – palliative care and bereavement

Immediate:

- L10: The room and environment must be prepared to meet the palliative care needs and wishes of the patient and their partner/family/carers, and allow them the privacy needed to feel that they can express their feelings freely.
- L19: The lead doctor/named nurse will inform the hospital bereavement team that a patient is dying. They should only be introduced to the partner/family or carers before a death has occurred, if they have specifically requested to meet them.
- L22: Informing hospital and community staff that there has been a death will fall to the identified lead doctor and/or named nurse in the hospital.
- L23: Contact details of agreed, named professionals within the ACHD cardiology team and bereavement team will be provided to the patient's partner/family or carers at the time they leave hospital.
- L25: Within one working week after a death, the specialist nurse, or other named support, will contact the family at a mutually agreed time and location.
- L26: Within six weeks of the death, the identified lead doctor will write to invite the partner/family or carers to visit the hospital team to discuss the patient's death. This should, where possible, be timed to follow the results of a post-mortem or coroner's investigation. The partner/family or carers will be offered both verbal and written information that explains clearly and accurately the treatment plan, any complications and the cause of death. Partners/families or carers who wish to visit the hospital before their formal appointment should be made welcome by the ward team.
- L27: When a centre is informed of an unexpected death, in another hospital or in the community, the identified lead doctor will contact the partner/family or carers.
- L28: If partners/families or carers are seeking more formal ongoing support, the identified Specialist ACHD Nurse/named nurse will liaise with appropriate services to arrange this.
- L9:For patients remaining in hospital, a named member of the nursing and medical staff will be identified during every shift so that they and their partner/family or carers can easily seek answers to questions and express wishes, worries and fears.



Key Gaps – Adult Centres

Section M – Dental

Immediate:

- M4: All patients admitted and diagnosed with infective endocarditis must have a dental assessment within 72 hours.
- 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.
- M5: Local ACHD Centres must either provide access to theatre facilities and appropriate anaesthetic support for the provision of specialist-led dental treatment under general anaesthetic for people with congenital heart disease or refer such patients to the Specialist ACHD Surgical Centre.

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.