DOWNS SYNDROME SUGGESTED SCHEDULE OF HEALTH CHECKS - CLINICAL GUIDELINE
1. **Aim/Purpose of this Guideline**

1.1. This guideline is designed to support neonatal staff to provide appropriate investigation, referrals and management of babies with a clinical diagnosis of Down Syndrome

2. **The Guidance**

2.1 **Cardiac: around 50% have cardiac problems**
Needs senior review, ECG and discussion with paediatrician with cardiac expertise. Those with abnormal clinical signs or ECG abnormality (in particular a superior QRS axis) are potentially at high risk and should be referred and seen within 2 weeks of birth for expert clinical assessment and echocardiogram. Pre and post ductal sats needed. Those with no abnormal clinical signs or ECG abnormality on initial examination may nevertheless have cardiac disease. These babies should all be referred and seen within 6 weeks of birth by a paediatrician with cardiac expertise for further assessment and an echocardiogram.

2.2 **Thyroid: about 10% develop hypothyroidism**
- Routine newborn blood spot screening
- From 1 year - thyroid function discussed annually using results of annual finger prick TSH OR 2 yearly thyroid blood test including thyroid antibodies

2.3 **Hearing: >50% have hearing impairment**
- Routine newborn screening OAEs (AABRs if in NNU > 48 Hours)
- Refer to audiology for review by 8 months of age for hearing and impedance check

2.4 **Eye checks: many ophthalmic problems more common**
- Routine newborn check including cataract check, repeated at 6 weeks by GP.
- Routine referral to Ophthalmologist with paediatric interest

2.5 **Developmental:**
- Refer to paediatric developmental physiotherapy – form on NNU.
- Refer to community paediatric consultant routinely.

2.6 **Growth Monitoring:**
- Plotted on Down Syndrome growth chart from birth until pre-school

2.7 **Blood Checks:**
- Newborn FBC to check for abnormal film
Appendix A

Downs Syndrome Suggested Schedule of Health Checks

Clinical Suspicion of Down Syndrome

Senior Medical Review

Clinical suspicion of Down Syndrome confirmed
Parents counselled
Information given at appropriate stage

Referrals to make
1. Cardiology
2. Audiology
3. Physiotherapy
4. Community Paediatrics
5. Ophthalmology
6. Paediatric follow up

Tests/Investigations/checks to do
1. Consent fo2 chromosome
2. Send chromosomes
3. Clinical cardiac review
4. Eye check
5. Full blood count
6. Hearing test
7. Blood spot screening

Not considered to have Down Syndrome

Parents reassured
Appendix B

Newborn Checklist for Down Syndrome

Baby examined by Senior Medical staff/Consultant, parents counselled

Consent for chromosomes.

Chromosomes sent to Bristol via Maxims

New patient information pack given to Parents - including Red Book inserts

**Cardiac:** – referral made to Paediatrician with expertise in Cardiology

**Hearing:** – routine newborn screen. Ensure diagnosis entered on Badger as this will generate 8 month formal review. Refer to Audiology on Maxims

Ensure diagnosis is entered on Badger as this audiology will generate FU

Refer to audiology by letter on Maxim’s (safety net)

**Eyes:** - Routine newborn examination including cataract check.

Refer to paediatric ophthalmology routinely (if normal) by letter on Maxim’s

**Thyroid:** - Newborn blood spot completed.

**Developmental:** - Refer to Paediatric Physiotherapists. Forms on NNU.

Refer Community Paediatricians routinely by letter on Maxims

Acute Paediatrician FU arranged
3. Monitoring compliance and effectiveness

<table>
<thead>
<tr>
<th>Element to be monitored</th>
<th>Ad hoc review of cases</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lead</td>
<td>Mr Paul Munyard, Consultant Neonates</td>
</tr>
<tr>
<td>Tool</td>
<td>Ad hoc review of cases</td>
</tr>
<tr>
<td>Frequency</td>
<td>annual</td>
</tr>
<tr>
<td>Reporting arrangements</td>
<td>Neonatal Guidelines Group</td>
</tr>
<tr>
<td>Acting on recommendations and Lead(s)</td>
<td>Neonatal Guidelines Group</td>
</tr>
<tr>
<td>Change in practice and lessons to be shared</td>
<td>Required changes to practice will be identified and actioned within 3 months. A lead member of the team will be identified to take each change forward where appropriate. Lessons will be shared with all the relevant stakeholders</td>
</tr>
</tbody>
</table>

4. Equality and Diversity

4.1. This document complies with the Royal Cornwall Hospitals NHS Trust service Equality and Diversity statement which can be found in the ‘Equality, Diversity & Human Rights Policy’ or the Equality and Diversity website.

4.2. Equality Impact Assessment

The Initial Equality Impact Assessment Screening Form is at Appendix 2.
### Appendix 1. Governance Information

<table>
<thead>
<tr>
<th>Document Title</th>
<th>DOWNS SYNDROME SUGGESTED SCHEDULE OF HEALTH CHECKS - CLINICAL GUIDELINE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date Issued/Approved:</td>
<td>14/06/2017</td>
</tr>
<tr>
<td>Date Valid From:</td>
<td>01/08/2017</td>
</tr>
<tr>
<td>Date Valid To:</td>
<td>01/08/2020</td>
</tr>
</tbody>
</table>
| Directorate / Department responsible (author/owner): | Dr Paul Munyard  
Consultant Neonatology |
| Contact details: | 01872 253293 |
| Brief summary of contents | All clinical staff working in the Division of women, children & sexual health to provide evidence based guidance in the suggested schedule of health checks for Downs Syndrome |
| Suggested Keywords: | Downs Syndrome, health checks schedule, Triosomy 21 |
| Target Audience | RCHT | PCH | CFT | KCCG |
| | ✓ | | | |
| Executive Director responsible for Policy: | Medical Director |
| Date revised: | 14/06/2017 |
| This document replaces (exact title of previous version): | New Document |
| Approval route (names of committees)/consultation: | Obstetric & Gynaecology Directorate meeting |
| Divisional Manager confirming approval processes | Mr David Smith |
| Name and Post Title of additional signatories: | Not Required |
| Signature of Executive Director giving approval | {Original Copy Signed} |
| Publication Location (refer to Policy on Policies – Approvals and Ratification): | Internet & Intranet | ✓ | Intranet Only |
| Document Library Folder/Sub Folder | |
| Links to key external standards | |
## Version Control Table

<table>
<thead>
<tr>
<th>Date</th>
<th>Version No</th>
<th>Summary of Changes</th>
<th>Changes Made by (Name and Job Title)</th>
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</thead>
<tbody>
<tr>
<td>14/06/2017</td>
<td>1.1</td>
<td></td>
<td>Paul Munyard Neonatal Consultant</td>
</tr>
</tbody>
</table>

All or part of this document can be released under the Freedom of Information Act 2000

This document is to be retained for 10 years from the date of expiry.

This document is only valid on the day of printing

**Controlled Document**

This document has been created following the Royal Cornwall Hospitals NHS Trust Policy on Document Production. It should not be altered in any way without the express permission of the author or their Line Manager.
## Appendix 2. Initial Equality Impact Assessment Form

<table>
<thead>
<tr>
<th>Name of the strategy / policy / proposal / service function to be assessed (hereafter referred to as policy) (Provide brief description):</th>
<th>Downs Syndrome Suggested Schedule of Health Checks</th>
</tr>
</thead>
<tbody>
<tr>
<td>Directorate and service area:</td>
<td>Neonatology</td>
</tr>
<tr>
<td>Is this a new or existing Policy?</td>
<td>New</td>
</tr>
<tr>
<td>Name of individual completing assessment: Mr Paul Munyard</td>
<td>Telephone: 01872 253293</td>
</tr>
</tbody>
</table>

1. **Policy Aim***
   Who is the strategy / policy / proposal / service function aimed at?
   - All clinical staff working in the Division of women, children & sexual health to provide evidence based guidance in the management of persistent bleeding following pregnancy

2. **Policy Objectives***
   - As above

3. **Policy – intended Outcomes***
   - As above

4. **How will you measure the outcome?**
   - See section 3

5. **Who is intended to benefit from the policy?**
   - All neonatal patients with Trisomy 21

6a) Is consultation required with the workforce, equality groups, local interest groups etc. around this policy?
   - No

   b) If yes, have these *groups been consulted?
   - C). Please list any groups who have been consulted about this procedure.

### 7. The Impact

Please complete the following table.

<table>
<thead>
<tr>
<th>Equality Strands</th>
<th>Yes</th>
<th>No</th>
<th>Rationale for Assessment / Existing Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>X</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Are there concerns that the policy **could** have differential impact on:
| Sex (male, female, transgender / gender reassignment) | X |
| Race / Ethnic communities /groups | X |
| Disability - learning disability, physical disability, sensory impairment and mental health problems | X |
| Religion / other beliefs | X |
| Marriage and civil partnership | X |
| Pregnancy and maternity | X |
| Sexual Orientation, Bisexual, Gay, heterosexual, Lesbian | X |

You will need to continue to a full Equality Impact Assessment if the following have been highlighted:
- You have ticked “Yes” in any column above and
- No consultation or evidence of there being consultation - this excludes any policies which have been identified as not requiring consultation. or
- Major service redesign or development

8. Please indicate if a full equality analysis is recommended.  Yes  No X

9. If you are not recommending a Full Impact assessment please explain why.

Signature of policy developer / lead manager / director

Date of completion and submission

Names and signatures of members carrying out the Screening Assessment
1. Dr Paul Munyard
2.

Keep one copy and send a copy to the Human Rights, Equality and Inclusion Lead, c/o Royal Cornwall Hospitals NHS Trust, Human Resources Department, Knowledge Spa, Truro, Cornwall, TR1 3HD

A summary of the results will be published on the Trust’s web site.

Signed ____________________

Date ____________________