UK DCTN AGM/Steering Group Meeting Minutes
Online
13 October 2020


Other Network members: A Proctor, L Kirby, I Traore, A Chan, Z Zaidi.

Guests: Miriam Santer, Ingrid Muller, Noreen Akram.


Actions

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<th>Action/ Resolution</th>
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<tr>
<td>MM to inform Sarah Worboys and Helen Young of their successful Steering Committee nominations</td>
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<td>MM to follow up with acne programme team after meeting to circulate meeting notes and author agreement form</td>
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<tr>
<td>CL to follow up with EczemaDoc team after meeting to circulate meeting notes</td>
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Minutes

1. Welcome and introductions

H Williams welcomed all those in attendance and thanked everyone for taking the time to attend our AGM which was being held virtually for the first time due to the COVID-19 pandemic. He welcomed presenters Miriam Santer, Ingrid Muller, and Noreen Akram. Also international members joining today from the Canadian Dermatology Research Network (C-NeST), and Guinea. This is last meeting for UK DCTN Fellows Alistair Brown and Zoe Tsianou, and patient representative Patricia Fairbrother. All were thanked for their excellent contributions to the steering group.

H Williams provided latest news on Network Studies:

- HI Light vitiligo study published in British Journal of Dermatology this month. Video here: [https://mediaspace.nottingham.ac.uk/media/1_2thazs0i](https://mediaspace.nottingham.ac.uk/media/1_2thazs0i)

- BEACON eczema Study (platform trial of systemic treatments for severe eczema), the team are awaiting final confirmation of their “fund with changes” request from the NIHR Heath Technology Assessment Programme

2. Minutes of February 2020 UK DCTN Steering Group meeting and matters arising
Previous minutes were confirmed as a true record and approved. The main actions were relating to the ongoing work with the SCC-AFTER study (which has now been submitted at outline stage to the NIHR) and the Heals study.

3. AGM Business

Finance
C Layfield presented the financial report relating to the charity bank accounts. In summary the outgoings did not exceed income for the year and the BAD and Shernaz Walton were thanked for their generous donations (10K to fund the 2019 Themed call and 1K respectively). Account balance looks healthy but there are several commitments for the coming year with the fellowships and themed call awards.

Nomination of new steering group members
Two new steering group were nominated and seconded as follows:
   i. Sarah Worboys - Nominated by C Layfield seconded by A Sears
   ii. Helen Young - Nominated by M McPhee seconded by C Flohr

4. Trial Generation & Prioritisation Panel (TGPP) update

   • 2021 Trainee Groups (R Matin, TGPP Chair) Members of the panel have been developing the programme for 2021. This will be the fourth cohort of UK DCTN Trainee Groups and new initiatives include an initial short online training session for, reformatting the final study day and the introduction of mentors with statistics and trial design expertise. There is no specific theme for this cohort so that the groups are free decide which research topic they would like to pursue. The plan is to advertise applications from Nov 2020, with a deadline in early 2021 with research days planned for 2nd March and 20th September.

   • UK DCTN Trainees Journal club (F Tasker, UK DCTN SpR Fellow) F Tasker and other past and present UK DCTN Fellows have initiated an online journal club for trainees to learn more about critical appraisal of dermatology studies on Zoom. After a short survey to trainees, it was found that few of them had access to a journal club to discuss research. The online format was advertised (with one hour sessions on a different topic bi-monthly). There was interest from over 70 people but a decision was made to keep the attendee numbers for each journal club limited to around 15 people to keep it manageable. Participants are required to read and respond to a publication before the session. The first journal club was held on 24th Sept with the recording made available afterwards to all on the mailing list. The next session is scheduled for 5 November. There will be a journal club page on the UK DCTN website soon to act as a repository for the recordings so they will be more widely accessible for all.

   J Ingram reported that the RCTs published in the British Journal of Dermatology have powerpoint slides available and could be used in the journal club.

   • Dragons Den
R Matin reported on this idea to help generate more research ideas and encourage people to come forward with proposals for new clinical trials. It aims to allow research proposals that might be at a very early stage that need discussing and thinking through. The process had not been finalised but it would be similar to the 'vipers nest' run by the Reconstructive Surgery Trials Network.

5. MAIN AGENDA ITEM – New studies

i. Programme Grant vignette - Acne
I Muller presented this large programme of work on acne. The main aim is to improve outcomes for people with acne by promoting appropriate treatment use and reducing overuse of long-term oral antibiotics.

There are three main work streams planned:

**Workstream 1: Intervention development** - Develop an online intervention for young people (13-25) with mild/moderate acne to support effective treatment use. This will be achieved by the following methods:
- Build expert advisory group
- Update systematic review of qualitative studies
- Qualitative interviews (young people, primary care prescribers, pharmacists)
- Create online intervention using the Person-Based Approach

**Workstream 2: RCT of intervention** – Online trial with individual randomisation to intervention or usual care. Primary outcome: Acne QoL symptoms subscale at 12 weeks.

**Workstream 3: Knowledge mobilisation in HCPs** - Develop a brief intervention aimed at health professionals’ management of acne and then explore usability and acceptability of the HCP intervention.

**Discussion followed with the points below raised:**

- It is key to engage with GPs and pharmacists on this programme of work given that community medicine deals with acne patients most frequently.

- The project could lead to an effective hand-held decision aid on a phone/paper for patients to take to their pharmacist.

- It was noted that NICE guidelines on acne treatments are in progress.

- There is a need to consider the long term viability for the online intervention, eg where will the app be housed. Age range of 13 years to 25 years olds – need a good behavioural model to capture the data because a 13 year old is very different to a 25 year old. Team hope to adapt it for all ages or reduce age from 25. Suggested to also include from 11 year olds? Consider promoting via TikTok to capture younger age range

- Antibiotics – if there is lot of overuse it should be emphasised to potential funders that it is something that needs addressing. Need to build better evidence of inappropriate antibiotic use, as the actual evidence might not be as strong as expected.

- Patients tend to visit GP quite late when acne has got quite bad so antibiotics are prescribed when topicals have not been tried for long enough.

- More convincing alignment with the acne priority setting partnership (PSP) questions was queried

- How will the study team ensure including people with mild/moderate acne when recruiting on social media? The acne may be worse than this and this may skew results

- Young people need support for adherence to treatment and progression of treatment.

- Recruiting via social media can be challenging. Acne PSP used a social media company with great success. SAFA experience has been that a company was not so useful but that a CTU intern was highly successful in this area.

- How to ensure targeting on minority/ethnic groups? Targeting different geographical areas and engaging with specific groups may be useful.
• Engage with teenagers using ‘influencers’ on Instagram. Establish social media presence very early on. Create content so that you gain followers prior to study. Hire interns and enthusiastic people to post and communication going on social media channels. Also join existing acne groups on social media.
• Consultant Dermatologist Anjali Mahto has a good following on Twitter and social media so recommended to engage with them also.

H Williams summarised discussion and asked group to vote to indicate their support for the project. Majority showed hands in favour of continued support from UK DCTN.

ii. Trial proposal vignette - Eczema App
Tracking and Self-Management Smartphone Application for Eczema-‘EczemaDoc’

N Akram presented a proposal for RCT to investigate the feasibility of the EczemaDoc (ED) app in reducing disease severity and improving QOL, over a period of time. Also to explore users’ perceptions of ED, over a variety of critical themes. Initially a small study with 80 patients (adults) to test the app compared with standard care. Prototype developed and tested in a small group. Need to develop further. Team would like UK DCTN to help design the study and validate the app.

The app has 3 components: track – patients can input their condition and triggers, understanding - by correlating the information, educate – advice and hints to best manage their condition. An app could be more convenient method to record and monitor their condition.

Current apps do not follow NICE guidelines or have the educational element and none have been evaluated by RCT.

Discussion points:
• Patients who have had eczema for a long time tend to already know their condition and their triggers.
• Build up of information through use of the app will eventually create some correlations between possible triggers and flares but only have basic version of the app available now.
• Good to propose an RCT for an app intervention, this probably hasn’t been done before. Is the app ready to test? This was confirmed to not be the case.
• Appears to be a substantial commercial element in the team that would make it not eligible for UKDCTN support.
• Seeking funding from investors and ‘crowd funding’.
• The RCT proposed is too broad, an RCT needs to be more focused need specific endpoints for an RCT.
• It is unclear how to ensure participants don’t use other apps in the study?
• How would it collect environmental data – indicated the phone collects this sort of date routinely
• Need to more fully review other apps on the market as lots are already available and in development. What’s popular already and how many downloads.
• Need to emphasise added value as patients will be sharing their data on it. Need a pilot study first to begin testing the value of the app.

• Be aware of the data collection and governance around gathering this data (GDPR) and the need to be transparent. Team indicated they have consulted with a data protection officer.

• Refine predictive ability of app before considering an RCT.

• Some crossover with ECO- Eczema Care Online, a behavioural intervention for eczema.

• Suggestion to contact Birmingham Clinical Trials Unit for further advice on development

• A Proctor of National Eczema Society offered to discuss the potential of the app further with the team.

H Williams summarised discussion and asked group to vote to indicate their support for the project. There were no votes to show continued support from UK DCTN. Steering group felt that this study is not ready for an RCT, the app needs more development work. UK DCTN doesn't generally support commercial studies but understand that apps have a commercial element. Some apps are free on NHS.

6. Trials in development and PSP updates

Ongoing trials and trials in development

• Ongoing studies SAFA, ALPHA and Theseus were paused due to the pandemic but each are now gradually opening and recruiting again.

• Beacon eczema study awaiting final confirmation funding from the NIHR HTA Programme, hopefully to be confirmed soon.

• RAPID study and the COUNT study were unsuccessful at outline stage application (NIHR Programme grant and HTA schemes respectively). Teams working out next steps and revised applications.

• SCC -AFTER working closely with Birmingham CTU and outline application submitted to NIHR HTA.

Priority Setting Partnerships (PSPs)

Pemphigus & Pemphigoid PSP - includes Bullous Pemphigoid, Pemphigus Vulgaris and Mucous Membrane Pemphigoid. First round survey completed (950+ questions submitted) – now pulling indicative questions together for second round survey.

Skin Cancer Surgery PSP - first meetings held, progressing very well. Joint funded by UK DCTN and BSDS.

7. AOB

Reminder re deadline 2020 Themed Call Psychological Interventions Mon 30th Nov

Date of next UK DCTN Steering Committee meeting

1.30pm 2nd February 2021
Online