ERS CRC “CONNECT” - Moving multiple digital innovations towards connected respiratory care

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Key Words:	electronic monitoring, ehealth, mobile devices, artificial intelligence, machine learning, digital adherence technology
Abstract:	

ERJ EDITORIAL

ERS CRC "CONNECT" - Moving multiple digital innovations towards connected respiratory care: addressing the over-arching challenges of whole systems implementation

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Twitter text: New ERS CRC "CONNECT" aims to accelerate implementation of digital respiratory health technology

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Introduction

In summer 2023, the European Respiratory Society (ERS) welcomed a new Clinical Research Collaboration (CRC) focused on implementation of digital respiratory health: "*CONNECT" - Moving multiple digital innovations towards connected respiratory care: addressing the over-arching challenges of whole systems implementation*. Historically, CRCs aim to foster research collaboration and stimulate joint grant applications around single respiratory diseases [1,2]. In an innovative approach, "CONNECT" spans all respiratory diseases and ERS Assemblies, thereby not only connecting humans and digital devices, and patients with healthcare professionals, but also linking existing CRCs within the ERS. In this editorial, we introduce the rationale, aims and working groups of "CONNECT".

Rationale

Digital technology pervades all aspects of contemporary life [3]. The European Union (EU) and World Health Organization (WHO) encourage policies that harness technology to make healthcare more patient-centered [4], and provide efficient accessible care [5] including for vulnerable populations and those living in remote areas [6]. The latter aim is especially critical to prevent inequities arising from the "digital divide", with the potential for the most needy being the least able to access essential technology [7]. The COVID-19 pandemic has demonstrated the value of 'data-enabled healthcare'. However, cross-border harmonisation is needed [8], as are assurances that technology is suitable for those with limited eHealth literacy and that personal data are protected [3]. Patients and healthcare professionals must also be kept abreast of the potential of artificial intelligence (AI) to support healthcare decisions [8].

Digital respiratory care is an ERS priority. No attendee of recent ERS Congresses could miss the accelerating interest in digital health, with sessions focused on digital care, frequent speaker references to digital initiatives, and abstracts describing diverse innovative digital projects [9, 10]. A Presidential Summit on *'Digital respiratory medicine – realism vs futurism*' in 2021 [11], the creation of the mHealth/eHealth ERS Group [12], and the commissioning of clinical reviews on telehealth [13], all testify to the Society's focus on digital respiratory care.

Recent advances in eHealth technology exploit the potential of the Internet-of-Things to enhance digital medicine and therapeutics ('DTx') [13]. Novel respiratory technologies include connected spirometers, smart inhalers and spacers, tuberculosis treatment monitored by electronic pill bottles, clinical decision support that use AI for radiological diagnosis and digitally-assisted home ventilation [14-17]. Digital health offers patients information, biofeedback, environmental data, access to diagnostics, support for

medication adherence and self-management [18, 19]. Moreover, remote consulting, essential in the pandemic, has become a permanent fixture in healthcare delivery [20].

Challenges

The evidence for digital health technologies is reaching a critical mass and the focus is changing from pilot/effectiveness studies in narrow clinical contexts, selected populations or single geographical locations to sustainable implementation underpinning routine clinical care. However, successful implementation is complex requiring insight into patient, professional and organisational perspectives (e.g. acceptability, digital health literacy, access), within the political, regulatory and socio-economic context [21].

A critical challenge is the lack of a unified system to capture data, calculate metrics, and integrate with electronic medical records which can diminish (and sometimes nullify) the benefits of digital monitoring. Successful implementation of innovative technology is further hampered by diverse healthcare systems, varying (or no) reimbursement pathways for eHealth, and inconsistent interpretation of digital policy regulations (e.g. European Medicines Agency (EMA)/Food and Drug Administration (FDA)/Digital Health Applications (DiGA) data privacy requirements). Given the likelihood and potential for rapid scale-up in the near future, cross-border harmonisation of standards is urgently required. In Europe this is being addressed by the European Health Data Space [22], which has been welcomed by the ERS as an opportunity to advance healthcare, research and policy-making [23].

Patient and public views

The European Lung Foundation adopted digital health as the theme for its Patient Organisational Day (2021) and has run workshops on digital health to explore potential benefits and concerns [24]. Patients are keen to use apps to monitor their condition and receive timely advice. They appreciate the convenience of remote consulting and highlight the impact (positive and negative) that digital healthcare could have on their relationship with healthcare professionals. They are willing to consider secondary use of their health data but have concerns about data privacy and security. Qualitative research has identified similar barriers and facilitators for use of digital respiratory technologies [25-27].

Healthcare professionals' view

Whatever the policy or disease context, significant organisational changes are needed to establish and sustain digital healthcare. These include practical resources, skills training, proper reimbursement, integration with existing patient management systems, transferability of data across settings, and privacy issues [21, 28]. The COVID pandemic illustrates how important the clinician involvement in this switch will be. Forced to adopt remote consultations, healthcare professionals accepted telephone or video-

consultations, but quickly realized that remote consulting was not always time-efficient or cost-effective [29, 30]. Echoing patient concerns, professionals highlighted the potential loss of empathy and 'human-ness' in remote consultations, when healthcare professionals and patients cannot see/touch each other [30]. This was a particular concern when an interaction was not built on an existing relationship [30, 31].

Thus, an over-arching digital implementation strategy that firmly considers the clinician perspective of workload and patient interaction is required, which is the overall theme of this CRC.

The history of CONNECT

A multidisciplinary group at the ERS Congress 2019 called for standards defining quality and implementation of digital healthcare, ideally developed by an academic respiratory society. The ERS Presidential Summit in 2021 explored this challenge with themes on the gains/losses with virtual respiratory care, core skills for respiratory professionals, approaches to evaluation and the policy/regulatory/ethical context [11]. At an ERS Research Seminar in 2022 on implementation of digital technologies, the multinational/multidisciplinary delegates (patients (ELF), clinicians, researchers, industry, policy makers/regulators), identified key over-arching themes: digital inequities; professional/patient rapport and trust; validated digital end-points; understanding policy, regulatory, socio-economic contexts. These themes evolved in wider discussions with ERS Assembly members and other disease-focused CRC leads [32, 33], but remain central to our objectives.

Vision and aims of CONNECT

CONNECT's long-term vision is of a cross-border, interoperable connected digital ecosystem, centered around the needs and preferences of the individual with respiratory disease who, in discussion with their healthcare professional, can choose the digital health and environmental data they record and share. These data cannot only support self-management, but can also be shared with (and between) their healthcare adviser(s) and (with consent) donated for research and public health purposes. In contrast, current digital healthcare typically is disease or device-specific, and often geographically focused with limited potential for incorporating multimorbidity, or flexibly reflecting individual preferences or clinical status.

The immediate-to-short term goals of CONNECT are (I) to create a network of stakeholders who will work collaboratively toward evidence-based, economically viable, implementation of respiratory eHealth centered on the person with respiratory disease, with structured evaluation that identifies and builds on benefits, addresses concerns and prevents harms. The means to do so include (II) the creation of an open access EU-wide repository of respiratory healthcare technologies, supporting findability and uptake of

digital technologies, (III) scoping published research on implementation strategies, (IV) developing position papers (e.g. on specific needs and challenges in vulnerable populations such as children, elderly and those with low literacy) and core outcomes sets of digital endpoints for clinical trials, ideally in close collaboration with regulators such as the EMA, and (V) using these as stepping stones to secure future funding and projects (Figure 1). One of these potential funding sources could emerge through collaboration with the DRAGON project (https://www.imi.europa.eu/projects-results/project-factsheets/dragon).

[FIGURE 1]

Structure and future plans of CONNECT

To realise CONNECT's goals, we are establishing a global network of colleagues interested in digital respiratory care. Regular newsletters and video-conferences will update members about opportunities to volunteer for a working group or be part of funding application(s). A structure has been established with a dedicated leadership team and several working groups with defined deliverables. Each working group is led by a group chair and a research fellow who are part of the leadership team, and will work with multidisciplinary volunteers drawn from the network, focusing on the specific deliverable. The overall CONNECT leadership is advised by a high-level expert advisory group, an ELF-coordinated digital health patient working group, and a funding partners panel ~~(Figure 2)~~. Advantages of this model include the breadth of professional and methodological expertise available within the network, and the knowledge of multiple healthcare systems and languages that can be called upon to support the various projects.

~~**[FIGURE 2]**~~

Where to find additional information and how to join CONNECT?

CONNECT currently has representation from all ERS Assemblies and disease-oriented CRCs. At the time of the ERS Congress 2023, over 800 people had expressed interest in joining CONNECT by completing the form accessed by scanning the QR code in Figure 1. More information on CONNECT can be found at https://www.ersnet.org/science-and-research/clinical-research-collaboration-application-programme/connect-moving-multiple-digital-innovations-towards-connected-respiratory-care-addressing-the-over-arching-challenges-of-whole-systems-implementation/

Digital transformation in respiratory medical care is already happening. CONNECT aims to understand and influence implementation so that processes are standardised, disadvantages are recognised and overcome, approaches are equitable and benefits are optimised to leave no one behind. We invite everyone sharing our goals to join the network and volunteer for one (or more) of our working groups.

Acknowledgements

The authors would like to thank all people that expressed interest in CONNECT and already joined one or more working groups. Also, we would like to acknowledge the input of the expert advisory group (Arzu Yorgancıoğlu, David Price, Anita Simonds, Jerry Krishnan, Dennis Falzon and Barbara Hoffman) during the design of this CRC.

Conflicts of interest

JVMvB and HP co-chair the CONNECT CRC; DD, AHYC, MH, CYH, IA, IC, KH, VP and RC are members of the CONNECT core leadership team.

JFMvB received grants and/or consultancy fees from Aardex, AstraZeneca, Chiesi, Lung Alliance Netherlands, European Commission COST (COST Action 19132 “ENABLE”), GSK, Novartis, Pfizer, Pill Connect, Teva, Trudell Medical and Vertex, outside the submitted work and all paid to his institution. DD is the secretary of the ERS group 1.04 mHealth/eHealth. He is the principal investigator of the clinical trial JoeCare (NCT04942639) funded by the company Ludocare. AHYC reports research grants from Health Research Council of New Zealand, Auckland Medical Research Foundation, Asthma UK, University of Auckland, Oakley Mental Health Foundation, Chorus Ltd, World Health Organisation, Hong Kong University, and consultancy fees from Breathing and Medical Ltd outside the submitted work and all paid to her institution (the University of Auckland). She is the previous holder of a Robert Irwin Postdoctoral Fellowship. AHYC also reports consultancy fees from AcademeX and Spoonful of Sugar Ltd, and is a Board member of Asthma NZ., member of the Respiratory Effectiveness Group (REG). MH has received funding from GlaxoSmithKline, Astra Zeneca, Novartis, Sanofi and Teva for unrestricted grants, speaker fees, consultancies, and contracted research, all unrelated to this work, and all paid to his employer Alfred Health. CyH is a visitor researcher in digital health at the University of Edinburgh, and is a senior consultant in net zero and sustainability (healthcare) at Turner and Townsend. Her research with the University of Edinburgh, is independent from, and not financially supported by Turner and Townsend. Her views in this publication are her own, and not those of Turner and Townsend. Neither she, nor Turner and Townsend, stand to gain financially from this work. IA reports previous PhD studentship funding by a GSK investigator-led grant and speakers fees from GSK for participation in an educational meeting. IA is a member of the British Thoracic Society Asthma Specialist Advisory Group. IC is CEO at Health Circuit, a spin-off company of Clínic Barcelona. RWC has received funding from BioNTech, GlaxoSmithKline, Astra Zeneca, Novartis, Respirasense and Teva in the form of unrestricted grants, speaker fees, consultancies, and contracted research, all unrelated to this work, and all paid to his employer. RWC is a founder of Phyxiom, a spin-off company of RCSI. HP has received research grants from national funding bodies paid to her University in the fields of digital health and implementation research. Other authors declare to conflicts of interest.

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FIGURE LEGENDS

FIGURE 1 Goals of ERS CRC CONNECT

~~**FIGURE 2** Working group structure of ERS CRC CONNECT~~

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CONNECT's long-term vision is of a cross-border, interoperable connected digital ecosystem, centered around the needs and preferences of the individual with respiratory disease who, in discussion with their healthcare professional, can choose the digital health and environmental data they record and share. These data cannot only support self-management, but can also be shared with (and between) their healthcare adviser(s) and (with consent) donated for research and public health purposes. In contrast, current digital healthcare typically is disease or device-specific, and often geographically focused with limited potential for incorporating multimorbidity, or flexibly reflecting individual preferences or clinical status.

The immediate-to-short term goals of CONNECT are (I) to create a network of stakeholders who will work collaboratively toward evidence-based, economically viable, implementation of respiratory eHealth centered on the person with respiratory disease, with structured evaluation that identifies and builds on benefits, addresses concerns and prevents harms. The means to do so include (II) the creation of an open access EU-wide repository of respiratory healthcare technologies, supporting findability and uptake of

digital technologies, (III) scoping published research on implementation strategies, (IV) developing position papers (e.g. on specific needs and challenges in vulnerable populations such as children, elderly and those with low literacy) and core outcomes sets of digital endpoints for clinical trials, ideally in close collaboration with regulators such as the EMA, and (V) using these as stepping stones to secure future funding and projects (Figure 1). One of these potential funding sources could emerge through collaboration with the DRAGON project (https://www.imi.europa.eu/projects-results/project-factsheets/dragon).

[FIGURE 1]

Structure and future plans of CONNECT

To realise CONNECT's goals, we are establishing a global network of colleagues interested in digital respiratory care. Regular newsletters and video-conferences will update members about opportunities to volunteer for a working group or be part of funding application(s). A structure has been established with a dedicated leadership team and several working groups with defined deliverables. Each working group is led by a group chair and a research fellow who are part of the leadership team, and will work with multidisciplinary volunteers drawn from the network, focusing on the specific deliverable. The overall CONNECT leadership is advised by a high-level expert advisory group, an ELF-coordinated digital health patient working group, and a funding partners panel. Advantages of this model include the breadth of professional and methodological expertise available within the network, and the knowledge of multiple healthcare systems and languages that can be called upon to support the various projects.

Where to find additional information and how to join CONNECT?

CONNECT currently has representation from all ERS Assemblies and disease-oriented CRCs. At the time of the ERS Congress 2023, over 800 people had expressed interest in joining CONNECT by completing the form accessed by scanning the QR code in Figure 1. More information on CONNECT can be found at https://www.ersnet.org/science-and-research/clinical-research-collaboration-application-programme/connect-moving-multiple-digital-innovations-towards-connected-respiratory-care-addressing-the-over-arching-challenges-of-whole-systems-implementation/

Digital transformation in respiratory medical care is already happening. CONNECT aims to understand and influence implementation so that processes are standardised, disadvantages are recognised and overcome, approaches are equitable and benefits are optimised to leave no one behind. We invite everyone sharing our goals to join the network and volunteer for one (or more) of our working groups.

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Conflicts of interest

JVMvB and HP co-chair the CONNECT CRC; DD, AHYC, MH, CYH, IA, IC, KH, VP and RC are members of the CONNECT core leadership team.

JFMvB received grants and/or consultancy fees from Aardex, AstraZeneca, Chiesi, Lung Alliance Netherlands, European Commission COST (COST Action 19132 “ENABLE”), GSK, Novartis, Pfizer, Pill Connect, Teva, Trudell Medical and Vertex, outside the submitted work and all paid to his institution. DD is the secretary of the ERS group 1.04 mHealth/eHealth. He is the principal investigator of the clinical trial JoeCare (NCT04942639) funded by the company Ludocare. AHYC reports research grants from Health Research Council of New Zealand, Auckland Medical Research Foundation, Asthma UK, University of Auckland, Oakley Mental Health Foundation, Chorus Ltd, World Health Organisation, Hong Kong University, and consultancy fees from Breathing and Medical Ltd outside the submitted work and all paid to her institution (the University of Auckland). She is the previous holder of a Robert Irwin Postdoctoral Fellowship. AHYC also reports consultancy fees from AcademeX and Spoonful of Sugar Ltd, and is a Board member of Asthma NZ., member of the Respiratory Effectiveness Group (REG). MH has received funding from GlaxoSmithKline, Astra Zeneca, Novartis, Sanofi and Teva for unrestricted grants, speaker fees, consultancies, and contracted research, all unrelated to this work, and all paid to his employer Alfred Health. CyH is a visitor researcher in digital health at the University of Edinburgh, and is a senior consultant in net zero and sustainability (healthcare) at Turner and Townsend. Her research with the University of Edinburgh, is independent from, and not financially supported by Turner and Townsend. Her views in this publication are her own, and not those of Turner and Townsend. Neither she, nor Turner and Townsend, stand to gain financially from this work. IA reports previous PhD studentship funding by a GSK investigator-led grant and speakers fees from GSK for participation in an educational meeting. IA is a member of the British Thoracic Society Asthma Specialist Advisory Group. IC is CEO at Health Circuit, a spin-off company of Clínic Barcelona. RWC has received funding from BioNTech, GlaxoSmithKline, Astra Zeneca, Novartis, Respirasense and Teva in the form of unrestricted grants, speaker fees, consultancies, and contracted research, all unrelated to this work, and all paid to his employer. RWC is a founder of Phyxiom, a spin-off company of RCSI. HP has received research grants from national funding bodies paid to her University in the fields of digital health and implementation research. Other authors declare to conflicts of interest.

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FIGURE LEGENDS

FIGURE 1 Goals of ERS CRC CONNECT

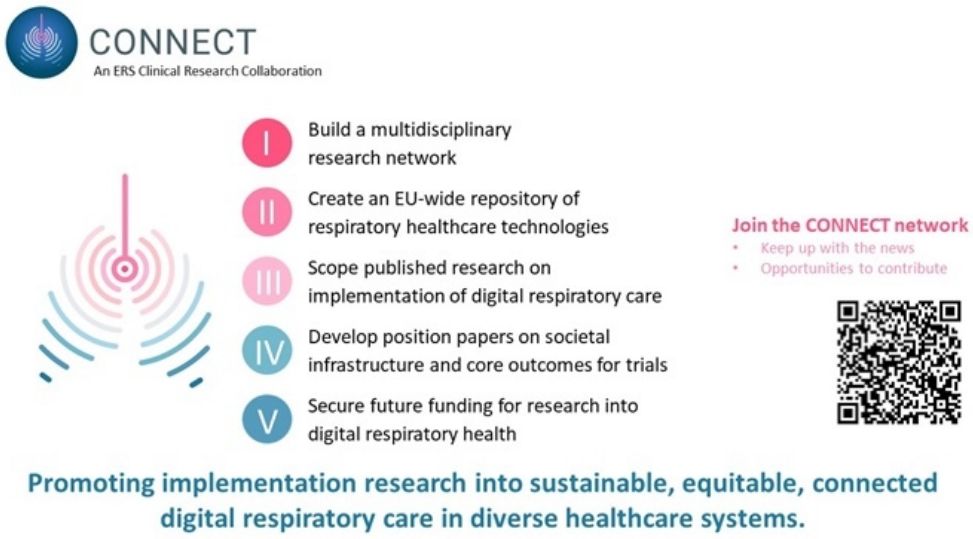

FIGURE 1 Goals of ERS CRC CONNECT

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