

# CV – Ewa-Lena Bratt

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## Work address

Institute of Health and Care Sciences  
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## Work experience

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1. **University lecturer** associated with a position as specialist nurse at the pediatric cardiology department, Queen Silvia Children's hospital, Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University. 16th March 2001 – present day.
2. **Assistant university lecturer** at the Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University. 1st March 2014 – 29th February 2016
3. **University lecturer** at the Institute of Health Sciences, University West, Trollhättan. 1st November 2011 – 29th February 2016.
4. **Nurse/specialist nurse**, Pediatric cardiology department, Queen Silvia Children's Hospital, Gothenburg. 16th June 1998 – to present day.

## Qualifications/titles

1. **Docent (Associate Professor) of Caring Sciences**, Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University. 18th April – 2018
2. **Consultant nurse**, Pediatric cardiology department, Queen Silvia Children's Hospital, Gothenburg. 1st December 2017
3. **PhD in Medicine** 28th October 2011 (240 credits) Institute of Clinical Sciences, Pediatrics Department, Sahlgrenska Academy, Gothenburg University, Gothenburg. Title of thesis: Screening for Hypertrophic Cardiomyopathy in Asymptomatic Children and Adolescents. Psychosocial consequences and impact on quality of life and physical activity. ISBN/ISSN 978-91-628-8340-9. <http://hdl.handle.net/2077/27855>
4. **Specialist nursing degree** in healthcare for children and youths, June 2004 (60 credits) Institute of Health and Care Sciences, Gothenburg University.
5. **Nursing degree**, June 1998 (180 credits), University of Borås. Registered nurse with a Bachelor's degree in nursing.

## Other education and training

1. Research Leader Initiative – REAL. The initiative is designed for future research leaders and covers leadership, group development, grant writing, ethics and utilization. The course was given on eight separate occasions between August 2017 and May 2018.
2. Intervention mapping – developing theory-based and evidence-based programs. Maastricht University, Holland. 4-7<sup>th</sup> July 2016.
3. EU-teach. European training in Effective Adolescent Care and Health. Lausanne, Switzerland, 5-10<sup>th</sup> July, 2015. <http://www.unil.ch/euteach/en/home.html>
4. Academic leadership 15 credits. Vårdalsinstitutet (Lund and Stockholm) 2014.

5. Supervision of students during clinical placement II (basic level, 7.5 credits) Institute of Health and Care Sciences, Sahlgrenska Academy. Gothenburg University. June 2013\*
6. Supervision of PhD-students, (5 credits). Pedagogic development and interactive learning (PIL unit), Gothenburg University. December 2012\*
7. Supervision of students during clinical placement I (advanced level, 7.5 credits) Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University. June 2012\*
8. University pedagogics (15 credits), Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University, Gothenburg. June 2011\*
9. Pedagogics for PhD students (3 credits), Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University. Research level. April 2009\*
10. Managing and organising projects (7.5 credits) (5p), Advanced level, Gothenburg School of Business, Economics and Law. June 2007.
11. Nursing care for children and youths with congenital heart defects (7.5 credits) (5p). Advanced level. Institute of Health and Care Sciences, Gothenburg University. December 2002.
12. Pediatric cardiology (7.5 credits) (5p). Advanced level. Institute of Health and Care Sciences, Gothenburg University, December 2001
13. Pain and pain management (7.5 credits) (5p), University of Borås, 2000.

\*= *Pedagogics*

## Languages

English – good written and oral knowledge

## Scientific merits

### *Scientific publications*

1. Saarijärvi M, Moons P, Wallin L, Gyllensten H, **Bratt EL**. Transition program for adolescents with congenital heart disease in transition to adulthood: protocol for a mixed-methods process evaluation study (the STEPSTONES project). *BMJ Open*. 2019. Aug 2;9(8):e028229. doi: 10.1136/bmjopen-2018-028229.
1. **Bratt EL**, Järholm S, Ekman-Joelsson B, Johannsmeyer A, Carlsson SÅ, Mattsson LÅ, Mellander M. Parental Reactions, Distress and Sense of coherence after Prenatal versus Postnatal Diagnosis of Complex Congenital Heart Disease Accepted 11<sup>th</sup> July 2019. *Cardiology in the Young*.
2. Acuña Mora M, Saarijärvi M, Sparud-Lundin C, **Bratt EL**, Moons P, Goossens E. The scope of research on transfer and transition in young persons with chronic conditions. Accepted 19<sup>th</sup> July 2019. *Journal of Adolescent Health*.
3. Acuña Mora M, Saarijärvi M, Sparud-Lundin C, Moons P, **Bratt EL**. Empowering young persons with congenital heart disease: using intervention mapping to develop a transition program-the STEPSTONES project. Accepted Aug 2019. *Journal of Pediatric Nursing*
4. Elissa K, **Bratt EL**, Khatib S, Axelsson Å, Sparud-Lundin C. Self perceived Health status and sense of coherence in children with diabetes type 1 living at the West Bank, Palestine. *Journal of Transculture Nursing*. Jun 11 2019. doi: 10.1177/1043659619854509.
5. Acuña Mora M, Sparud-Lundin C, Burström Å, Hanseus Å, Rydberg A, Moons P, **Bratt EL**. Patient empowerment and its correlates in young persons with congenital heart disease. Accepted for publication on *European Journal of Cardiovascular Nursing*. March 2019. doi: 10.1177/1474515119835434
6. Burström Å, Acuña Mora M, Öjmyr-Joelsson M, Sparud-Lundin C, Rydberg A, Hanseus K, Frenckner B, Nisell M, Moons P, **Bratt EL**. Ready for transfer to adult care? - a triadic

- evaluation of transition readiness in adolescents with congenital heart disease and their parents. Aug 2019. *Journal of Family Nursing*. doi: 10.1177/1074840719864255
7. Burström Å, Acuña Mora M, Öjmyr-Joelsson M, Sparud-Lundin C, Rydberg A, Hanseus K, Frenckner B, Nisell M, Moons P, **Bratt EL**. Parental Uncertainty About Transferring Their Adolescent with Congenital Heart Disease to Adult Care. *Journal of Advanced Nursing*. 2019 Feb;75(2):380-387. doi: 10.1111/jan.13852.
  8. Acuña Mora M, Luyckx K, Sparud-Lundin C, Peeters M, van Staa A, Sattoe J, **Bratt EL**, Moons P. Patient empowerment in young persons with chronic conditions: psychometric properties of the Gothenburg Young Persons Empowerment Scale (GYPES). *PLoS One*. 2018 Jul 20;13(7). doi: 10.1371/journal.pone.0201007
  9. Elissa K, Sparud-Lundin C, Khatib S, Axelsson Å, **Bratt EL**. Struggling and Overcoming Daily Life Barriers among Children with Congenital Heart Disease and Their Parents in the West Bank, Palestine. *Journal of Family Nursing*. 2018, Nov 27: doi: 1074840718809710.
  10. **Bratt EL**, Burström Å, Hanseus K, Rydberg A, Berghammer M. Do not forget the parents- Parents concerns during transition to adult care for adolescents with congenital heart disease. *Child Care Health and Development*. 2018 Mar;44(2):278-284. doi:10.1111/cch.12529
  11. Burström Å, **Bratt EL**, Nisell M, Freckner B, Rydberg A, Hanseus K, Öjmyr-Joelsson M. Adolescents with congenital heart disease: their opinions about the preparation for transfer to adult care. *European Journal of Pediatrics*. 2017 Jul;176(7):881-889. doi: 10.1007/s00431-017-2917-9.
  12. Sparud-Lundin C, Berghammer M, Moons P, **Bratt EL**. Health Care Providers Attitudes Towards Transfer and Transition in Young Persons With Long Term Illness and Special Health Care Needs. *BMC Health Services Research*. 2017 Apr 11;17(1):260. doi 10.1186/s12913-017-2192-5
  13. Acuna Mora M, Sparud-Lundin S, **Bratt EL**, Moons P. Person-centered transition program to empower adolescents with congenital heart disease in the transition to adulthood: study protocol for a hybrid randomized controlled trial (STEPSTONES project). *BMJ Open*. 2017 Apr 17;7(4):e014593. doi. 10.1136/bmjopen-2016-014593
  14. Elissa K, **Bratt EL**, Khatib S, Axelsson Å, Sparud-Lundin C. Societal Norms and Conditions and their Influence on Daily life in Children with Type 1 Diabetes in the West Bank in Palestine. *Journal of Pediatric Nursing* 2017 Mar - Apr;33:16-22. doi: 0.1016/j.pedn.2016.12.005
  15. Acuña Mora M, Moons P, Sparud-Lundin C, **Bratt EL**, Goossens E. Assessing the level of evidence on transfer and transition in young people with chronic conditions: protocol of a scoping review. *Systematic Reviews*. 2016 Sep 29;5(1):166. doi.10.1186/s13643-016-0344-z
  16. **Bratt EL**, Järholm S, Ekman Joelsson B-M, Mattsson L-Å, Mellander M. Parent's experiences of counselling and their need for support following a prenatal diagnosis of congenital heart disease - a qualitative study in a Swedish context. *BMC Pregnancy and childbirth*. 2015 Aug 15;15(1):171. doi: 10.1186/s12884-015-0610-4.
  17. **Bratt EL**, Luyckx K, Goossen E, Budts W, Moons P, for the i-DETACH investigators. Patient-Reported Health in Young People with Congenital Heart Disease transitioning to adulthood. *Journal of Adolescent Health*. 2015 Dec;57(6):658-65. doi: 10.1016/j.jadohealth.2015.07.021.
  18. **Bratt EL**, Moons P. Forty Years of Quality-of-Life Research in Congenital Heart Disease: Temporal Trends in Conceptual and Methodological Rigor. *International Journal of Cardiology*. 2015 Sep 15;195:1-6.15. doi: 10.1016/j.ijcard.2015.05.070.

19. Burström Å, Öjmyr-Joelsson M, **Bratt EL**, Lundell B, Nisell M. Adolescents with Congenital Heart Disease and their parents - Needs before transfer to adult care. *Journal of Cardiovascular Nursing*. 2016 Sep-Oct;31(5):399-404. doi: 10.1097/JCN.0000000000000288
20. Asp A, **Bratt EL**, Bramhagen AC. Transfer to adult care - Experiences of young adults with Congenital Heart Disease. *Journal of Pediatric Nursing*. 2015 Sep-Oct;30(5):e3-e10. doi: 10.1016/j.pedn.2015.05.025.
21. Samuelsson, S, Willén C, **Bratt EL**. New kid on the block?" Community nurses' experiences of caring for sick children at home in Sweden. *Journal of Clinical Nursing*. 2015. Sep;24(17-18):2448-57 doi: 10.1111/jocn.12823
22. **Bratt EL**, Östman-Smith I. Effects of life-style changes and high dose beta-blocker therapy on exercise capacity in children, adolescents and young adults with hypertrophic cardiomyopathy. *Cardiology in the Young*. 2015 Mar;25(3):501-10. doi: 10.1017/S1047951114000237
23. **Bratt EL**, Östman-Smith I, Axelsson ÅB, Berntsson L. Quality of life in asymptomatic children and adolescents before and after diagnosis of hypertrophic cardiomyopathy through family screening. *Journal of Clinical Nursing*. 2013 Jan; 22(1-2):211-21. Doi: 10.1111/j.1365-2702.2012.04108
24. **Bratt EL**, Sparud-Lundin C, Östman-Smith I, Axelsson ÅB. The experience of being diagnosed with hypertrophic cardiomyopathy through family screening. *Cardiology in the Young*. 2012 Oct;22(5):528-35. doi: 10.1017/S1047951111002101
25. **Bratt EL**, Östman-Smith, I, Sparud-Lundin, C, Axelsson, ÅB. Parents' experiences of having an asymptomatic child diagnosed with hypertrophic cardiomyopathy through family screening. *Cardiology in the Young*. 2011 Feb; 21(1):8-14. Doi: 10.1017/S1047951110001290
26. Östman-Smith I, Wisten A, Nylander E, **Bratt EL**, de-Wahl Granelli A, Oulhaj A, Ljungström E. Electrocardiographic amplitudes: a new riskfactor for sudden death in hypertrophic cardiomyopathy. *European Heart Journal*. 2010 Feb;31(4):439-49. Doi: 10.1093/eurheartj/ehp443

### Submitted manuscripts

1. Elissa K, Sparud-Lundin C, Khatib S, Axelsson Å, **Bratt EL**. Children with congenital heart disease living on the West Bank, Palestine - Health status and sense of coherence.
2. Skogby S, Moons P, Johansson B, Christersson C, Nagy E, Winberg P, Hanseus K, Krzynska A, Fadl S, Fernlund E, Kazamia P, Rydberg A, Sunnegårdh J, Goossens E, **Bratt EL**. Patient Volumes and Medical Staffing Recourses as Predictors for Continuity of Follow-up Care during Transfer of Adolescents with Congenital Heart Disease

### Manuscripts

1. Saarijärvi M, Acuna Mora M, Moons P, Sparud-Lundin C, Goossens E, **Bratt EL**. Is it transfer, transition or both? Scope of research on transfer and transition in young persons with chronic conditions.
2. Saarijärvi M, Wallin L, Moons P, Gyllensten H, **Bratt EL**. Who are we missing? Comparison of participants and non-participants in a transition program for adolescents with congenital heart disease: assessment of reach and external validity of the STEPSTONES study
3. Brorsson AL, **Bratt EL**, Moons P, Sparud-Lundin C. A person-centered transition program to empower adolescents with type 1 Diabetes: a study protocol (STEPSTONES project)

## Conference contributions – accepted abstracts

1. Östman-Smith I, Allahyari P, **Bratt EL**, Pettersson M. In a prospective randomized study in familial hypertrophic cardiomyopathy, metoprolol maintains exercise-performance, with lower myocardial oxygen-cost, and prevents deterioration in exercise-ability. European Society of Cardiology-ESC congress. Paris, France 31 Aug-4 Sept 2019.
2. Burström Å, Acuna Mora M, Sparud-Lundin C, Ryberg A, Hanséus K, Moons P, **Bratt EL**. Lack of Knowledge about Contraception and Pregnancy in Adolescent Girls with Congenital Heart Disease – There is Room for Improvement. 53rd Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 15-18 May 2019, Seville, Spain.
3. Forsman Grankvist F, Järholm S, Ekman-Joelsson B, Mattson LÅ, Mellander M, **Bratt EL**. Reactions of Mothers and Fathers after Prenatal or Postnatal Diagnosis of Congenital Heart Disease. 53rd Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 15-18 May 2019, Seville, Spain.
4. **Bratt EL**, Saarijärvi M, Acuna Mora M, Sparud-Lundin C, Moons C. Transition program to empower adolescents with chronic conditions in their transition to adulthood: methods and rationale for the STEPSTONES project. Forte talks 26-27 March 2019. Stockholm. [www.fortetalks.se](http://www.fortetalks.se)
5. **Bratt EL**, Acuna Mora M, Saarijärvi M, Brorsson AL, Skogby S, Sparud-Lundin C. Person-centered and Empowering Care for Adolescents with Chronic Conditions during Transition to Adulthood – workshop. SAHM 2019 Annual Meeting Psychological Well-being: International Transcultural Perspectives. March 6-9, 2019 Washington Marriott Wardman Park Washington, DC, USA.
6. Burström Å, Acuña Mora M, Sparud-Lundin C, Rydberg A, Hanséus K, Moons P, **Bratt EL**. Parents' experience of uncertainty related to transfer from pediatrics to adult care in adolescents with congenital heart disease. SAHM 2019 Annual Meeting Psychological Well-being: International Transcultural Perspectives. March 6-9, 2019 Washington Marriott Wardman Park Washington, DC, USA
7. Skogby S, **Bratt EL**, Johansson, B, Moons P, Goossens E. Urgency for Clarification of Concepts and Definitions related to Discontinuation of Follow-Up Care for Young People with Complex Chronic Conditions. 3rd CARE4 – International Scientific Nursing and Midwifery Congress 2019. 4-6 February 2019. Leuven, Belgium.
8. **Bratt EL**, Zühlke L, Mayosi B, Skogby S, Joachim A, Jiyana S, Msomi T, Pepeta L, Moons P. Unraveling the role of healthcare system factors for continuing care of adolescents with congenital or rheumatic heart disease: Rationale and methods of the international Adole7C-project. 19<sup>th</sup> Annual South African Heart Association Congress. 4-7 October 2018. Suncity, South Africa.
9. Acuña Mora M, Moons P, Burström Å, Sparud-Lundin C, Rydberg A, Hanséus K, **Bratt EL**. Illness perceptions in adolescents with congenital heart disease and its association with patient reported outcomes. European Society of Cardiology Congress. 25-29 August 2018. Munich, Germany.
10. Acuña Mora M, Saarijärvi M, Sparud Lundin C, **Bratt EL**, Moons P, Goossens E. Mapping the field: scoping reviews as a method to identify gaps in nursing research. Nordic Conference of Nursing Research. 13-15 June 2018.
11. Saarijärvi M, Acuña Mora M, **Bratt EL**, Sparud Lundin C, Moons P, Goossens E. Scoping the fields of transfer and transition in young persons with cardiovascular conditions. Euro Heart Care. 7-9 June 2018. Dublin. Ireland.

12. Burström Å, Acuña Mora M, Öjmyr-Joelsson M, Sparud-Lundin C, Rydberg A, Hanseus K, Frenckner B, Nisell M, Moons P, **Bratt EL**. Ready for the transfer to the adult care – factors associated with transition readiness in adolescents with congenital heart disease. 52<sup>nd</sup> Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 9-11 May 2018, Athens, Greece.
13. Mellander M, Järholm S, Ekman-Joelsson B, Johannsmeyer A, Carlsson S.-Å, Mattsson L-Å, **Bratt EL**. Parental Psychological Distress after Prenatal versus Postnatal Diagnosis of Congenital Heart Disease. 52<sup>nd</sup> Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 9-11 May 2018, Athens, Greece.
14. Skogby S, Moons P, Johansson B, Dellborg M, Christersson C, Nagy E, Winberg P, Thilen U, Hanseus K, Krzynska A, Fadl S, Fernlund E, Kamazia P, Rydberg A, Sunnegårdh J, Goossens E, **Bratt EL**. Successful transfer to adult care: A nationwide study in patients with complex congenital heart lesions in Sweden. 52<sup>nd</sup> Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 9-11 May 2018, Athens, Greece.
15. Acuna Mora, M. Sparud-Lundin, C. Burström, Å. Hanseus, K. Rydberg, A. Moons, P. **Bratt, EL**. Level of empowerment and its correlates in young persons with congenital heart disease. European Society of Cardiology Congress. 26-30 August 2017. Barcelona, Spain.
16. Burström, Å. Acuna Mora, M. Sparud-Lundin, C. Hanseus, K. Rydberg, A. Öjmyr-Joelsson, M. Nisell, M. Frenckner, B. Moons, P. **Bratt, EL**. Readiness for transfer in adolescents with congenital heart disease. 7th World congress of Pediatric Cardiology and Cardiac Surgery. 16-21 July 2017. Barcelona, Spain.
17. Elissa K, Khatib S, Axelsson Å, Sparud-Lundin C, **Bratt EL**. Sociocultural Beliefs and Social Pressure in Everyday Life of Children Living With Congenital Heart Disease In the Palestinian West Bank. 7th World congress of Pediatric Cardiology and Cardiac Surgery. 16-21 July 2017. Barcelona, Spain.
18. **Bratt EL**, Sparud-Lundin C, Acuña Mora M, Moons P. The STEPSTONES project – Effectiveness of a transition program to empower adolescents with congenital heart disease in the transition to adulthood. ISTAR conference (Individual Self-esteem and Transition to Adolescence with Respect). Enablers and barriers for successful transition from childhood to adulthood. 19-21 June 2017, Borås.
19. Sparud-Lundin C, Berghammer M, Moons P, **Bratt EL**. Health care providers' attitudes towards transfer and transition in young persons with long term illness. ISTAR conference (Individual Self-esteem and Transition to Adolescence with Respect). Enablers and barriers for successful transition from childhood to adulthood. 19-21 June 2017, Borås.
20. Sparud-Lundin C, Berghammer M, Moons P, **Bratt EL**. Nurses' and doctors' perceptions of transfer of youths with long-term conditions from pediatric to adult healthcare Children's Week, 24-27 April 2017. Gothenburg. Poster presentation (Swedish).
21. Högstedt J, Meldo J, **Bratt EL**. Youths with heart conditions – experiences of being a young in-patient at a children's hospital. Children's Week, 24-27th April 2017, Gothenburg. Poster presentation (Swedish).
22. Acuña Mora M, Sparud-Lundin C, Luyckx K, **Bratt EL**, Moons P. Empowerment in congenital heart disease: psychometric properties of the Gothenburg Young Persons Empowerment Scale (GYPES). EuroHeart Care. May 2017, Jönköping.
23. Acuña Mora M, Moons P, Sparud-Lundin C, **Bratt EL**. Using intervention mapping in developing complex nursing interventions - the STEPSTONES transition program for

adolescents with chronic conditions. The Future Direction of European Nursing and Nursing Research. Jointly convened by the European Academy of Nursing Science & the Swedish Society of Nursing. Malmö 4-7 July, 2017.

24. Wadman E, Sörensen M, **Bratt EL**. Special diets to reduce pleural effusion after cardiac surgery in children with complex heart disease – effect or not? Nordic meeting in Pediatric Cardiology and Cardiac surgery. Båstad, 21-23 September 2016.
25. **Bratt EL**, Burström Å, Hanseus K, Rydberg A, Berghammer M. Adolescents with congenital heart disease – parent’s perceptions and expectations about transition and transfer to adult care. Nordic meeting in Pediatric Cardiology and Cardiac surgery. Båstad, 21-23 September 2016.
26. Högstedt J, Meldo J, **Bratt EL**. Youths hospitalized in a pediatric ward – experiences of adolescents with congenital heart disease. Nordic meeting in Pediatric Cardiology and Cardiac surgery. Båstad, 21-23 September 2016.
27. Acuña Mora M, **Bratt EL**, Sparud-Lundin C, Moons P. Hybrid experimental design: A suitable design to tackle contamination of control groups. Nordic Conference in Nursing Research. Stockholm 15-17 June 2016.
28. Burström Å, **Bratt EL**, Frenckner B, Nisell M, Rydberg A, Hanseus K, Öjmyr-Joelsson M. Responsibility, knowledge and trust – Important aspects in the preparation to the transfer to adult care. 50<sup>th</sup> Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 2-4 June 2016, Rome, Italy.
29. Moons P, Sparud-Lundin C, Acuña Mora M, **Bratt EL**. Effectiveness of a transition program to empower adolescents with congenital heart disease in the transition to adulthood: Rationale and methods of the STEPSTONES-ConHD project. 50<sup>th</sup> Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 2-4 June 2016, Rome, Italy.
30. Burström Å, Öjmyr-Joelsson, **Bratt EL**, Lundell B, Nisell M. Young people with congenital heart disease need to be prepared for the shift in responsibility - Safety and Trust during Transfer to adult care. 49<sup>th</sup> Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 20-23 May 2015, Prague, Czech Republic.
31. Burström Å, **Bratt EL**, Nisell M, Hanseus K, Rydberg A, Frenckner B, Öjmyr-Joelsson M. Young people with Congenital Heart Disease. How to prepare for adult care – their own perspective? 49<sup>th</sup> Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 20-23 May 2015, Prague, Czech Republic.
32. Asp A, **Bratt EL**, Bramhagen AC. Experiences of transfer to adult healthcare. Young adults with congenital heart defects. Children’s Week 20-23 April 2015, Stockholm (Swedish).
33. **Bratt EL**, Luyckx K, Goossens E, Budts W, Moons P. Scrutinizing Patient-Reported Health Status in Young People with Congenital Heart Disease 18<sup>th</sup> Annual Update on Pediatric and Congenital Cardiovascular Disease - Challenges and Dilemmas. Feb 11-15, 2015. Scottsdale, Arizona, USA.
34. **Bratt EL**, Järvholm S, Ekman Joelsson B-M, Johannsmeyer A, Carlsson S-Å, Matsson L-Å, Mellander M. Continuing pregnancy following a prenatal diagnosis of a cardiac defect: What support do parents need? Cardiology 2015. 18<sup>th</sup> Annual Update on Pediatric and Congenital Cardiovascular Disease. Challenges and Dilemmas. Feb 11-15, 2015. Scottsdale, Arizona, US.
35. **Bratt EL**, Östman-Smith I. Effects of life-style changes and high dose beta-blocker therapy on exercise capacity in children and young adults with hypertrophic cardiomyopathy. Nordic Pediatric Cardiology Meeting. 19-21 sept 2014. Copenhagen, Denmark.

36. Samuelson S, Willén C, **Bratt EL**. New kid on the block? Community nurses' experiences of caring for sick children at home. The American Academy of Nursing Transforming Health Driving Policy Conference in Washington 16-18th October 2014.
37. **Bratt EL**, Östman-Smith I. Compliance with lifestyle recommendations in children and young adults with hypertrophic cardiomyopathy. 6th World Congress in Paediatric Cardiology & Cardiac surgery, 17-22 February 2013. Capetown, South Africa.
38. **Bratt EL**, Sparud-Lundin C, Östman-Smith I, Axelsson Å.B. The experience of being diagnosed with hypertrophic cardiomyopathy through family screening in childhood and adolescence. 46th Annual Meeting of the Association for European Paediatric and Congenital Cardiology. 23-26 May 2012, Istanbul, Turkey.
39. **Bratt EL**, Berntsson L, Axelsson A, Östman-Smith I. Quality of life in asymptomatic children and adolescents before and after diagnosis of hypertrophic cardiomyopathy through family screening. *Cardiol Young*; Vol 21. Suppl 1. p S1-167 (2011). (Page S50 PW 4-5). 45th Annual Meeting of the Association for European Paediatric and Congenital Cardiology, Granada, Spain.
40. **Bratt EL**, Östman-Smith I, Sparud-Lundin C, Axelsson A. Parents' experiences of having an asymptomatic child diagnosed with hypertrophic cardiomyopathy through family-screening. *Eur J Cardiovasc Nurs*, Vol 9. Suppl. (2010). (Page S8). 10th Annual Spring Meeting on Cardiovascular Nursing, Geneva, Switzerland. Awarded prize for best poster presentation.
41. **Bratt EL**, Östman-Smith I, Axelsson A. Parents' experiences of having an asymptomatic child diagnosed with hypertrophic cardiomyopathy through family-screening. 5th World Congress of Paediatric Cardiology and Cardiac surgery, Cairns, Australia. [www.pccs2009.com](http://www.pccs2009.com).
42. **Bratt EL**, de-Wahl Granelli A, Östman-Smith I. Selective or non-selective high-dose betablockers – evaluation of exercise capacity in children and adolescents with hypertrophic cardiomyopathy. 5th World Congress of Paediatric Cardiology and Cardiac surgery, Cairns, Australia. [www.pccs2009.com](http://www.pccs2009.com).
43. **Bratt EL**, de-Wahl Granelli A, Östman-Smith I. Effect of high-dose betablocker therapy on exercise capacity in young adults, adolescents and children with hypertrophic cardiomyopathy. *Scand Cardiovasc J*; Vol 41. Suppl (2007). IX Swedish Cardiovascular Spring meeting 2007, Gothenburg.
44. Östman-Smith I, **Bratt EL**, de-Wahl Granelli A. Frequency of diagnostic ECG-abnormalities in children of parents with familial hypertrophic cardiomyopathy. *Scand Cardiovasc J*; Vol 41 suppl (2007). IX Swedish Cardiovascular Spring meeting 2007, Gothenburg.
45. **Bratt EL**, de-Wahl Granelli A, Östman-Smith I. Effect of high-dose betablocker therapy on exercise capacity in patients with hypertrophic cardiomyopathy. *Cardiol Young*; Vol 17. Suppl 1. p 40-41 (2007). 42nd Annual Meeting of the Association for European Paediatric and Congenital Cardiology, Warsawa, Poland.
46. **Bratt EL**, de-Wahl Granelli A, Östman-Smith I. Clinically Important Differences in Accuracy of Different Pulse Oximeters in the Assessment of Children With Cyanotic Heart Disease. *Cardiol Young*. Vol 16. Suppl 2. p 73 (2006). 41st Annual Meeting of the Association for European Paediatric and Congenital Cardiology, Basel, Austria.
47. **Bratt EL**, de-Wahl Granelli A, Östman-Smith I. Inadequate documentation of family history in case notes of patients with Hypertrophic Cardiomyopathy hampers detection of children at potential risk? *Scand Cardiovasc J*; Vol 40. Issue 2. Suppl 54. (2006). p 32-33. VIII Swedish Cardiovascular Spring meeting, Linköping, 2006.
48. **Bratt EL**, Kornegård-Bark Å, Kokinsky E. The Use of Alfentanil During Chest tube Removal After Pediatric Cardiac Surgery in a Nursing Ward. The 4th World Congress of



Pediatric Cardiology and Cardiac Surgery, Buenos Aires, Argentina, September 18-22, 2005 (#171).

### Conference contributions – other

1. **Bratt EL.** Transition into adulthood – health care needs of adolescents with congenital heart disease. 52nd Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 9-11 May 2018, Athens, Greece. Invited speaker.
2. **Bratt EL.** Transition from pediatric to adult healthcare – congenital heart defects. Stepstones project. Children’s Week 23-26 April 2018, Västerås (Swedish). Invited speaker.
3. **Bratt EL.** Health care needs of adolescents with congenital heart disease: transition into adulthood. European Society of Cardiology Congress. 26-30 Aug 2017. Barcelona, Spain. Invited speaker.
4. **Bratt EL.** Challenges in Parenting a Child with Heart Disease. 7th World Congress of Pediatric Cardiology and Cardiac Surgery. 16-21 July 2017. Barcelona, Spain. Invited speaker.
5. **Bratt EL.** Psychosocial consequences for parents-to-be and their needs during pregnancy after diagnosis of heart defects in the unborn child. National meeting “Small hearts, Big choices” (Norwegian), 16 November 2016, Oslo. Invited speaker.
6. **Bratt EL, Sparud-Lundin C.** Stepstones project. Network meeting for PhD graduated pediatric nurses, 10-11 November, Uppsala. Invited speaker.
7. **Bratt EL.** The new AEPC Working Group ”Nursing and allied professions”. Nordic meeting in Pediatric Cardiology and Cardiac surgery. Båstad, 21-23 September 2016. Invited speaker.
8. **Bratt EL.** STEPSTONES - the Swedish transition project. Nordic meeting in Pediatric Cardiology and Cardiac surgery. Båstad, 21-23 September 2016. Invited speaker.
9. **Bratt EL.** Parenting during transition. 50<sup>th</sup> Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 2-4 June 2016, Rome, Italy. Invited speaker.
10. **Bratt EL.** Wellbeing in couples expecting a child with a heart disease. 50<sup>th</sup> Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 2-4 June 2016, Rome, Italy. Invited speaker.
11. **Bratt EL.** Stepstones - The Swedish Transition Project. National region days for pediatric heart care 12-13 May 2016. Gothenburg. Oral presentation.
12. **Bratt EL.** What education and support do couples need after a prenatal diagnosis of Congenital Heart Disease? 49<sup>th</sup> Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC) 20-23 May 2015, Prague, Czech Republic. Invited speaker.
13. **Bratt EL.** Prenatal diagnosis of heart defects – the experiences of parents-to-be. Cardiology healthcare staff. 27-28 November 2014, Jönköping. Training days – congenital heart defect working group for the Cardiology caring professions. Oral presentation (Swedish).
14. **Bratt EL, Gossens E, Moons P.** Optimal transition – ready to go? Cardiology healthcare staff – living with congenital heart defects from the perspective of the family and the profession. 27-28 November 2014. Jönköping. Oral presentation.
15. **Johansson A, Sloberg S, Bratt EL.** Patient education in adolescents with congenital heart disease – does a computer based program developed for adults work? 44th Nordic Paediatric Cardiology Meeting. Umeå. 17-19 September 2014. Invited speaker.

16. **Bratt, EL**, Carlsson S-Å, Ekman-Joelsson B-M, Johannsmeyer A, Järholm S, Matsson L-Å, Mellander M. Prenatal screening of congenital heart disease - What about the parents? Invited speaker. 44th Nordic Paediatric Cardiology Meeting. Umeå. 17-19 September 2014. Invited speaker
17. Moons P, Goossens E, **Bratt EL**. Transfer and transition in adolescents with congenital heart disease - What? Why? When and How? 44th Nordic Paediatric Cardiology Meeting. Umeå. 17-19 September 2014. Invited speaker.
18. **Bratt EL**, Goossens, E, Moons, P. Building up a transition programme for young people with congenital heart disease: What works? Joint Annual Meeting of the Swiss Society of Cardiology (SSC) and the Swiss society of Cardiac and Thoracic Vascular Surgery (SSCS). 12 June 2014, Interlaken, Switzerland. Invited speaker.
19. **Bratt EL**, Berghammer, M. Do we need a European network in congenital heart nursing? 48th Annual meeting of the European Association of Pediatric and Congenital Cardiology (AEPC). 23 May 2014, Helsinki, Finland. Invited speaker.
20. **Bratt EL**. Optimal transition – nurses’ view. 48th Annual meeting of the European Association of Pediatric and Congenital Cardiology (AEPC). 22 May 2014. Helsinki, Finland. Invited speaker.
21. **Bratt EL**. Family screening - psychosocial consequences. Genetic advisers’ annual meeting, Gothenburg. 11 April 2014. Invited speaker.
22. Moons P, Goossens E, **Bratt EL**. How do we improve patient knowledge? Cincinnati Summit June 10, 2014. Cincinnati (OH) USA.
23. **Bratt EL**. Diagnosis of familial asymptomatic HCM: impact of the diagnosis on quality of life. 41st Nordic Paediatric Cardiology Meeting, Helsinki, Finland. 15-17 Sept 2011. Invited speaker.
24. **Bratt EL**. Family screening for hereditary heart muscle disease. Psyke-och-soma convention 20-21 October 2011. Gothenburg. Invited speaker.  
[www.sahlgrenska.se/su/psykeochsoma2011](http://www.sahlgrenska.se/su/psykeochsoma2011).
25. **Bratt EL**. Experiences of diagnosis of Hypertrophic cardiomyopathy through family screening, how is daily life affected? Presentation at the Centre for Cardiovascular Genetics (CKG) at the Norrland University Hospital (NUS) Umeå. 5-6 Dec 2011. Invited speaker.
26. **Bratt EL**. The impact of pre-symptomatic screening diagnosis of hypertrophic cardiomyopathy through family screening. 46th Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC). 23-26 May 2012, Istanbul, Turkey. Invited speaker.
27. **Bratt EL**. Family screening for hypertrophic cardiomyopathy. Cardiogenetics convention. 14 September, 2012. Lund. Invited speaker.
28. **Bratt EL**. Family screening for hereditary heart muscle disease. Children’s Week. 26 April 2012, Borås, arranged by the Swedish Paediatric Society (BLF). Invited speaker.
29. **Bratt EL**. “Psychosocial consequences of diagnosis of hypertrophic cardiomyopathy in asymptomatic children through family screening”. 44th Annual Meeting of the Association for European Paediatric and Congenital Cardiology (AEPC), Innsbruck, Austria. May 2010. Invited speaker.
30. **Bratt EL**. “Pre and Postoperative care in the paediatric cardiac ward” Presentation at the Joint meeting in fetal and paediatric cardiology and paediatric cardiac surgery Royal Brompton Hospital – The Queen Silvia Children’s Hospital, 14-15 June 2007, Gothenburg. Oral presentation.
31. **Bratt EL**. “Pain assessment and Pain – therapy in the paediatric cardiac ward” Presentation at the Joint meeting in fetal and paediatric cardiology and paediatric cardiac

surgery Royal Brompton Hospital – The Queen Silvia Children’s Hospital, 14-15 June 2007, Gothenburg. Oral presentation.

32. Andersson Stavridis S, **Bratt EL**, Götlind U, Stang J. Evidence-based pediatric cardiology nursing. Presentation at the 2nd National Children’s Heart meeting, Västerås 6-8 October 2005. Oral presentation.
33. **Bratt EL**, Jansson U-B, Finnström B, Nilsson S. “Pain assessment in children – a standard procedure?” 6th International Symposium on Paediatric Pain: Pain in Childhood, the big Questions, Sydney, Australia. June 2003. Oral presentation.
34. Andersson Stavridis S, **Bratt EL**, Kornegård-Bark Å, Lundgren E, Wickert M, Wiklander Winsnes B. “Who’s the pediatric heart team at your hospital? An inventory of pediatric heart teams in Sweden”. 1st National Children’s Heart meeting. Halmstad. 2-4 May, 2002. [www.barn.halland.net/hjarta2002](http://www.barn.halland.net/hjarta2002). Oral presentation.

### Postdoctoral stays

1. KU Leuven Department of Public Health and Primary Care, Centre for Health Services and Nursing Research, Belgium. May 2014.
2. KU Leuven Department of Public Health and Primary Care, Centre for Health Services and Nursing Research, Belgium. Nov 2014.
3. Red Cross War Memorial Children’s Hospital and University of Capetown, South Africa. Nov-Dec 2016.

### Research stays

1. KU Leuven Department of Public Health and Primary Care, Centre for Health Services and Nursing Research, Belgium. June 2017.
2. KU Leuven Department of Public Health and Primary Care, Centre for Health Services and Nursing Research, Belgium. July 2018.
3. Red Cross War Memorial Children’s Hospital and University of Capetown, South Africa. Nov 2018.

### Other

Project work associated with my PhD project. Department of Cardiovascular Medicine, John Radcliff Hospital, Oxford, UK. March 2006.

### Popular science publications\*

1. Acuna Mora M, Saarijärvi M, **Bratt EL**. Stepstones – an ongoing study to improve transition to adult life for youths with congenital heart defects. Hjärtebarnet. No. 1. 2018
2. **Bratt EL**, Sparud-Lundin C. Youths with Chronic illnesses and their transfer from pediatric to adult healthcare – STEPSTONES – (Swedish Transition Effect Project Supporting Teenagers with Chronic Medical Conditions). Barnbladet. Aug 2016
3. **Bratt EL**. From child to adult – current research projects about young people with long-term conditions. STEPSTONES-ConHD. Hjärtebarnet. Jan Volume 2016 No. 1.
4. **Bratt EL**. From child to adult – current research projects about young people with long-term conditions. Barnbladet. Dec 2015.
5. **Bratt EL**. Expecting a child with a heart defect. Hjärtebarnet, Volume 2015, No. 4, 2015.
6. **Bratt EL**, Berghammer M. Creating the conditions for smooth transition from pediatric healthcare to adult healthcare. Barnbladet. Dec 2013.
7. **Bratt EL**. The path to adult healthcare. Hjärtebarnet. No. 4, 2012 Hjärtebarnet. 2012.

8. **Bratt EL.** Questions and answers about patient safety at four pediatric clinics in Sweden. Barnbladet 2012.
9. **Bratt EL.** Transition in pediatric healthcare. Barnbladet. Tidskrift för Sveriges Barnsjuksköterskor, 6/2011.
10. **Bratt EL.** From loose papers to paper-free! Barnbladet 2008;33(3)11
11. **Bratt EL.** Does surgery hurt? Can you measure pain? Hjärtebarnet. No. 1, 2004.
12. **Bratt EL,** Kornegård Bark Å; Kokinsky E Pain relief with Alfentanil (Rapifen) during removal of thorax drainage in hospitalised children who have undergone heart surgery. Barnbladet 2006;31(4)12-5.

\*Swedish publications. Titles translated for information.

## **Research grants received as main applicant**

### **2016**

Swedish Heart-Lung Foundation SEK 900 000 – project grant (SEK 300 000kr/p.a for three years). An integrative study on the role of hospital-related factors for continuing care of adolescents with congenital heart disease: The Adole7C-project (AdolesCents reCeiving Continuous Care for Childhood-onset Chronic Conditions).

### **2015**

Göteborgs Barnklinikers forskningsfond project grant SEK 15 000 for the project “Effectiveness of a transition program to empower adolescents with chronic conditions in the transition to adulthood: The STEPSTONES project”.

Sahlgrenska University Hospital fund project grant SEK 30 000 for the project "Effectiveness of a transition program to empower adolescents with chronic conditions in the transition to adulthood: The STEPSTONES project.

Hjärtebarnsfonden – project grant SEK 40 000 for the project "Effectiveness of a transition program to empower adolescents with chronic conditions in the transition to adulthood: The STEPSTONES project.

Swedish Heart-Lung Foundation SEK 300 000 – project grant. Prevalence, predictors and outcomes of lost-to-follow-up in patients with congenital heart disease – part of The STEPSTONES project.

### **2014**

Petter Silverskiölds memorial fund “Stepstones – CHD” project grant SEK 15 000.

Hjärtebarnsfonden – “Stepstones – CHD” project grant SEK 80 000.

### **2013**

FOU-VGR regional funding – research grant “Prenatal screening – psychosocial consequences” SEK 220 000.

Hjärtebarnsfonden – “Stepstones – CHD” project grant SEK 50 000.

### **2012**

Hjärtebarnsfonden – research grant “Pre-natal screening – psychosocial consequences” SEK

90 000.

### **2010**

Swedish Heart-Lung Foundation – PhD scholarship and travel funding SEK 54 000  
Petter Silverskiölds stiftelse - PhD scholarship SEK 30 000  
Mayblomman - PhD scholarship SEK 90 000

### **2009**

Swedish Heart-Lung Foundation – PhD scholarship and travel funding SEK 63 000  
Petter Silverskiölds stiftelse – PhD scholarship SEK 32 000

### **2008**

Hjärtebarnsfonden – PhD scholarship SEK 30 000

### **2007**

Märta och Gustaf Ågrens stiftelse – PhD scholarship SEK 100 000

### **2006**

Göteborgs Barnklinikers forskningsfond – PhD scholarship SEK 37 000

## **Received research grants as co-applicant**

### **2019**

**Diabetesfonden** – SEK 281 000. Comparative effectiveness of transitional care models for adolescents with Type 1 diabetes in the transition to adulthood: The STEPSTONES-DIAB project. Chief applicant Carina Sparud-Lundin. Ewa-Lena Bratt co-applicant. DIA2018-326.

### **2018**

**Barndiabetesfonden** – SEK 275 000. Comparative effectiveness of transitional care models for adolescents with Type 1 diabetes in the transition to adulthood: The STEPSTONES-DIAB project. Chief applicant Carina Sparud-Lundin. Ewa-Lena Bratt co-applicant.

### **2016**

**Forte/SAMRC** (South African Medical Research Council) – SEK 2 100 000 for the project “Resolving the role of healthcare system factors for the care gaps in adolescents with complex chronic conditions: An international, multilevel study (Adole7C)”. A collaboration with researchers from the University of Cape Town. Chief applicant: Professor Philip Moons. Ewa-Lena Bratt co-applicant (**project coordinator**).

### **2015**

**Forte** – **project grant** SEK 3 830 000 for the project “Effectiveness of a transition program to empower adolescents with chronic conditions in the transition to adulthood: The STEPSTONES project. Chief applicant and scientific leader Professor Philip Moons. Ewa-Lena Bratt co-applicant (**project coordinator**). **2015-00594**

**The Swedish Research Council** – **project grant** SEK 6 000 0000 for the project “Effectiveness of a transition program to empower adolescents with chronic conditions in the transition to adulthood: The STEPSTONES project”. Chief applicant and scientific leader, Professor Philip Moons. Ewa-Lena Bratt co-applicant (**project coordinator**). **2015 – 02503**

**Swedish Heart-Lung Foundation – project grant** 900 000 SEK for the project “Effectiveness of a transition program to empower adolescents with chronic conditions in the transition to adulthood: The STEPSTONES project”. Chief applicant and scientific leader, Professor Philip Moons. Ewa-Lena Bratt co-applicant (**project coordinator**).

## **2011**

**State funding: ALF-medel, Västra Götaland region.** SEK 1 325 000. Prospective randomised treatment trial and cohort studies to achieve better treatment and risk-stratification for fatal complications in children and adults with hypertrophic cardiomyopathy and improved early diagnosis of life-threatening congenital heart defects in new-borns. Diary no. ALFGBG-151911. Chief applicant: Professor Ingegerd Östman-Smith. Ewa-Lena Bratt co-applicant.

## **2008**

**Regional funding: FOU medel-Västra Götaland region.** SEK 230 000. Project: Network for better treatment and risk stratification for children and adults with hypertrophic cardiomyopathy: a hereditary heart disease with risk of sudden death. Diary no: VGFOUREG-35101. Chief applicant: Professor Ingegerd Östman-Smith. Ewa-Lena Bratt co-applicant.

**State funding: ALF-medel Västra Götaland region.** SEK 219 000. Improved detection and treatment of heart disease in children. Diary no: ALFGBG-11752. Chief applicant: Professor Ingegerd Östman-Smith. Ewa-Lena Bratt co-applicant.

## **2005**

**State funding: ALF-medel Västra Götaland region.** SEK 1 200 000. Improved detection and treatment of heart disease in children. Diary no: ALFGBG-3181. Chief applicant: Professor Ingegerd Östman-Smith. Ewa-Lena Bratt co-applicant.

### **Review assignments:**

2019 Cardiology in the young (1 review)  
2019 Acta Paediatrica (1 review)  
2019 Health and Quality of Life outcomes (2 reviews)  
2019 Scandinavian Journal of Caring Sciences (1 review)  
2019 Journal of Pediatric Nursing (1 review)  
2018 BMJ Open (1 review)  
2018 Journal of Adolescent Health (1 review)  
2018 Scandinavian Journal of Caring Sciences (2 reviews)  
2018 Journal of Pediatric Nursing (2 reviews)  
2017 Acta Paediatrica (1 review)  
2017 Journal of Pediatric Nursing (2 reviews)  
2017 Interantional Journal of Adolescent Medicine and Health (1 review)  
2017 JAMA Pediatrics (1 review)  
2016 Journal of Pediatric Nursing (1 review)  
2015 Sexuality Research and Social Policy (1 review)  
2015 JAMA Pediatrics (1 review)  
2015 Journal of Pediatric Nursing (3 reviews)  
2014 Cardiology in the Young (1 review)

2013 Cardiology in the Young (1 review)

2012 Cardiology in the Young (1 review)

### **Abstract reviewing:**

ESC (European Society of Cardiology) annual convention, Paris, France. Aug 2019

AEPC (Association for European Paediatric Cardiology) annual convention, Seville, Spain  
15-19 May 2019.

European Academy of Pediatric Societies, convention, Paris 2018.

AEPC (Association for European Paediatric Cardiology) annual convention in Athens,  
Greece. May 2018.

ESC (European Society of Cardiology) annual convention, Munich, Germany. Aug 2018

AEPC (Association for European Paediatric Cardiology) annual convention, Lyon, France.  
March 2017.

## **Supervision at research level**

### **Main supervisor**

Mariela Acuna Mora RN, MSc. PhD student at the Institute of Health and Care Sciences,  
Sahlgrenska Academy, Gothenburg University. Thesis title: Patient empowerment during  
transition to adulthood in young persons with chronic conditions: STEPSTONES- ConHD  
project. 2015- 2021. **Approved half-time seminar, Nov 2017.**

Sandra Skogby RN, MSc. PhD student at the Institute of Health and Care Sciences,  
Sahlgrenska Academy, Gothenburg University. Thesis title: Resolving the role of healthcare  
system factors for care gaps in adolescents with complex chronic conditions: An international,  
multilevel study. The Adole7C-project (AdolesCents reCeiving Continuous Care for  
Childhood-onset Chronic Conditions). 2017- 2022.

Markus Saarijärvi RN, MSc. PhD student at the Institute of Health and Care Sciences,  
Sahlgrenska Academy, Gothenburg University. Thesis title: Process of care and economic  
evaluation of a transition program to empower adolescents with chronic conditions in the  
transition to adulthood. The STEPSTONES-ConHD project. 2017- 2021. **Approved half-  
time seminar, June 2019.**

### **Co-supervisor**

Mikaela Hällström. PhD student at the Institute of Health and Care Sciences, Sahlgrenska  
Academy, Gothenburg University Thesis title: Comparative effectiveness and experiences of  
transitional care models for adolescents with Type 1 diabetes in the transition to adulthood: The  
STEPSTONES-DIAB project. 2019-2024.

Kawther Atallah Elissa RN, MScN Al-Quds University, Jerusalem and PhD student at the  
Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University. Thesis  
title “Children with chronic diseases and their families living in the West Bank”. 2014 - 2019.  
**Thesis defence, 190427.** <http://hdl.handle.net/2077/58500>

Åsa Burström MScN RN, PhD student at Karolinska Institutet, Stockholm. Thesis title:  
“Transition from Child Health Care to Adult Health Care for adolescents born with  
Congenital Heart Disease – A multicenter study”. **Thesis defence 180309** at Karolinska  
Institutet, Stockholm. <http://hdl.handle.net/10616/46190>

## Project leadership

### *Ongoing scientific work*

**Stepstones-CHD.** Swedish Transition Effect Project Supporting Teenagers with Chronic Medical Conditions – Congenital Heart Disease

The project is a multi-centre study, in collaboration with seven university hospitals: Gothenburg, Linköping, Lund, Stockholm, Umeå, Uppsala and Örebro.

**Background:** Medical advances have given individuals with congenital heart defects increased life expectancy. Lifelong medical follow-up optimises their potential to live well and for longer. Young people with congenital heart defects need to be prepared for the transition to adult healthcare and learn to assume responsibility for their health, participation and self-determination being important aspects. To facilitate this transition, transition programmes have been developed but concrete evidence of the effects of such programmes is lacking.

**Aims:** The project aims to develop a structured transition programme for young people with congenital heart defects and to examine the effects of such a programme on the individual's participation, self-determination and self-care ability. The hypothesis is that youths with congenital heart defects that undergo a structured, person-centred transition programme for a 2.5 year period (between the ages of 16-18) will have increased empowerment and show higher levels of participation and self-determination in regard to their health than youths who receive standard care.

**Working plan:** The study is being conducted at seven university hospitals in Sweden (Gothenburg, Lund, Linköping, Stockholm, Uppsala, Umeå and Örebro). At two centres (Gothenburg and Stockholm), 140 patients will be randomly selected to receive care according to current routines or be given a person-centred, structured transfer. 140 patients will be recruited from the centres which comprise the control groups, with continued care according to current routines. For a period of 2.5 years, a number of interventions will be implemented.

**Significance:** The study will provide scientific evidence as to whether transition programmes are effective or not. If increased participation and self-determination is achieved, this can influence self-care ability and as a result improve the prospects of young people with heart defects living well for longer. The results are also of significance to the allocation of healthcare resources. If the programme is not effective, Swedish healthcare will be spared the cost of ineffective measures. [www.stepstones-project.org](http://www.stepstones-project.org)

The project is registered on Clinical trials.gov: Trial registration number: NCT02675361

### **Significance of hospital-related factors for uninterrupted medical follow-up of young people with long-term conditions: Adole7C-project (AdolesCents reCeiving Continuous Care for Childhood-onset Chronic Conditions)**

The project is an international multi-centre study in collaboration with the seven university hospitals in Sweden (Gothenburg, Linköping, Lund, Stockholm, Umeå, Uppsala, Örebro), two hospitals in Belgium (Leuven and Gent) and two hospitals in South Africa (Capetown and Port Elizabeth).



## **Background**

Today, more than 90 % of people with congenital heart defects survive into adulthood. However, they cannot always be viewed as cured, and may therefore require lifelong medical follow-up. Despite this, some people with congenital heart defects cease medical follow-up after transferring to adult healthcare. This can lead to increased risk of complications and increased healthcare costs. International data has shown that between 21-76% of these patients are not under medical follow-up.

## **Aims**

On the basis of hospital-related factors in Sweden study: (i) proportion of patients with congenital heart defects who continued or discontinued their medical follow-up after transfer to adult healthcare, and at what care level any follow-up occurs; (ii) patient-proximal and hospital-related factors that predict patients will not be followed-up; (iii) consequences for sickness, mortality and healthcare consumption; (iv) obstacles to continued medical follow-up on the basis of the patients' perspective.

## **Working plan**

A longitudinal multi-centre study on the care of patients with congenital heart defects is being conducted at all seven university hospitals in Sweden (Gothenburg, Linköping, Lund, Stockholm, Umeå, Uppsala and Örebro). Patients are being included from lists of clinic visits dating from 2005-2011. Data on diagnosis and follow-up is being gathered, and on hospital-related factors. In 2020, patients who have continued medical follow-up will be compared with those who have not in relation to sickness, mortality and healthcare consumption. In-depth interviews with patients will also be conducted.

## **Significance**

The study will provide information on how many patients should be under medical follow-up and those who are not. Moreover, it will examine factors related to healthcare, allowing us to identify factors that may influence why people are lost to follow-up. As a whole, the study will contribute to reducing the current knowledge gap regarding incomplete follow-up of young people with congenital heart defects in Sweden.

## **Prenatal screening for heart defects – psychosocial consequences**

The project is a multi-centre study in collaboration with Gothenburg, Borås and Trollhättan/Vänersborg. Data collection is complete and analysis is ongoing.

**Background:** Heart malformations are the most common type of congenital defect – 800-1 000 babies per year are born with them in Sweden. Introducing prenatal screening for heart defects, which is now increasingly part of the routine ultrasound exams (RUL) in Sweden, puts the onus on caregivers to evaluate any potential negative effects of screening, including psychosocial ones. Moreover, it is important to establish what needs parents-to-be have during the period from diagnosis to delivery and to study their ability to handle this difficult situation. Well-developed cooperation between antenatal care and pediatric cardiology is a prerequisite for optimal care of both child and parents. However, there is a lack of evidence-based knowledge about the needs of parents-to-be and their perception of the information given.

**Aims:** To ascertain the information and support needs of parents-to-be in connection with specialist fetal cardiology examinations when fetal heart defects have been confirmed.

Moreover, to study the psychosocial consequences of such diagnostics, for example, the study participant's coping strategies and ability to handle the new situation compared to parents who received their diagnosis post-natally.

**Working plan:** The research programme consists of two studies in which parents' experiences of prenatal heart-defect diagnostics are studied by means of in-depth interviews, focusing on the need for support and information. Moreover, parents' psychological health will be examined in regard to apprehensions, anxiety and depression, as well as their coping ability related to prenatal or postnatal heart-defect diagnosis.

**Significance:** The studies aim to improve the way parents are cared for during pregnancy and the new-born period by identifying their needs and any negative psychosocial consequences of prenatal diagnosis. The results will serve as a foundation for shaping routines and guidelines for improved psychosocial support.

### **Research experience from other research groups**

I collaborate with a research group from KU Leuven, led by Professor Philip Moons in Belgium and with the University of Capetown, South Africa, led by Professor Liesel Zulcke. I have been on research stays at both universities.

### **Grading and assessment committee assignments**

Member of grading committee for Lena Larsson's PhD-thesis defence. Institute of Medicine, Sahlgrenska Academy, Gothenburg University. 13th June 2019.

Member of assessment committee for half-time seminar (M Frödin). Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University. 23rd Jan 2019.

Member of assessment committee for half-time seminar (R Schenell). Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University. 8th March 2018.

Member of review committee for PhD admission seminar (C Olofsson). Pediatrics Department, Institute of Clinical Sciences, Sahlgrenska Academy, Gothenburg University. 16th February 2018.

Member of assessment committee for half-way seminar (M Dellenmark). Pediatrics Department, Institute of Clinical Sciences, Sahlgrenska Academy, Gothenburg University. 13th Jan 2016.

### **Pedagogic merits**

#### **Teaching and pedagogic skills**

**Course examiner** Complex care situations course (7.5 credits), obligatory course on the nursing programme, Term 5. 2018-2019. Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University.

**Course leader for** Complex care situations course (7.5 credits), obligatory course on the nursing programme, Term 5. 2015-2017. Teaching, conducting seminars and written examination of the course. The course contains ABCDE simulation at the institution's clinical training centre and brief clinical training in units with complex care. Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University.

**Course leader for** Advanced nursing of children and adolescents with congenital heart defects (7.5 credits). Advanced level HT 2019. Commissioned course for the heart unit at Queen Silvia children's hospital, Gothenburg. Responsible for planning and course development. Teaching in lectures and seminars. Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University.

**Course leader for** Heart conditions in children and adolescents (7.5 credits) Advanced level 2016-2018. Commissioned course for the pediatric heart centre at Queen Silvia children's hospital, Gothenburg. Responsible for planning and course development. Teaching in lectures and seminars. Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University.

**Course leader for** Complex nursing situations (7.5 credits), optional course on the nursing programme, Term 5. 2014. Teaching, conducting seminars and oral och written examination of the course. Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University.

**Course leader for** Heart conditions in children and adolescents (7.5 credits) Advanced level *autumn term, 2012-2013*. Commissioned course for the pediatric heart unit at Queen Silvia Children's hospital, Gothenburg. Responsible for leading, planning and developing the course. Teaching in lectures and seminars. Institute of Health Sciences, University West, Trollhättan.

**Course leader for** Nursing of children and adolescents with heart conditions (7.5 credits) Advanced level, spring term 2013. Commissioned course for the pediatric heart unit, Queen Silvia Children's hospital, Gothenburg. Independent responsibility for leading, planning and developing the course. Teaching in lectures and seminars. Institute of Health Sciences, University West, Trollhättan.

**Chief supervisor** (20%) for clinical training for the academic healthcare programmes in pediatric cardiology, neonatal and pediatric intensive care. 2010-2014.

**Teaching** Course: Nursing sick children (7.5 credits) Basic level, 2012-2014. Institute of Health Sciences, University West, Trollhättan.

**Teaching** Course: Children's and adolescents' health and sickness (15 credits) Advanced level 2011-2013. Number of students on the course: 60. Institute of Health Sciences, University West, Trollhättan.

**Clinical training teacher responsible for clinical examinations** – in-patient or municipal home care and situation-oriented supervision. Course: Nursing for somatic conditions (22.5 credits) Basic level. 2012-2013 (Term 4, nursing programme). Institute of Health Sciences, University West, Trollhättan.

**Teaching** Course: Breastfeeding – theory and practice (7.5 credits). Commissioned course, Advanced level 2014. Institute of Health Sciences, University West, Trollhättan.

**Clinical training teacher responsible for clinical examinations (NKSE)** – in-patient or municipal home care. Course: Lead and develop professional nursing, Term 6, nursing programme, 2013. Institute of Health Sciences, University West, Trollhättan.

**Teaching** Course: Evaluating sick children and the needs of children and parents during a hospital stay within the course Complex care situations, 2015 – 2019. Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University.

**Teaching** Course: Introduction to nursing, first course, Term 1 of nursing programme. 2014-2015. Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University.

**Teaching** Course: Nursing in sickness and health – nursing children and adolescents, Term 3 of the nursing programme. 2015-2018. Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University.

**Teaching** Pediatric nursing programme. Course: Advanced evaluation and advanced care actions in health-promoting work for children and adolescents and their families. 2015-2018. Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University.

**Teaching** Pediatric nursing programme. Course: Advanced evaluation during illness in children and adolescents (7.5 credits) 2015-2019. Institute of Health and Care Sciences, Sahlgrenska Academy, Gothenburg University.

## **Internationalisation**

Responsible for developing the internationalisation of the course, Complex care situations (7.5 credits) on the nursing programme. From the spring of 2019, the course will be held in English. Incoming international students took this course in spring 2018 and spring 2019.

## **Recognition and prize for internationalisation 2019**

Received Sweden's medical faculty prize for internationalisation of higher education at basic and advanced level for internationalisation work on the course, Nursing in complex situations for the nursing programme at Sahlgrenska Academy, Gothenburg University. We have developed a concept that makes it possible to integrate incoming exchange students with the Swedish students on the nursing programme. In this way, incoming students are offered the opportunity to interact with the Swedish students in a global classroom, while the Swedish students gain an international perspective to their education, regardless of whether they go on an exchange themselves or not.

## **Autumn term 2018**

Within the framework for international staff mobility, I taught nursing students for a week at Al Quds University, Palestine (teaching basic level, masters students and tutors). 12-20 September 2018.

## **Spring 2015**

Teacher exchange via Linneus-Palme. I taught nursing students for three weeks at Al Quds University, Palestine (basic level and masters students). 6 - 26 March 2015.

## **Academic contact tutor for international exchange students participating in clinical training**

### **Spring term 2014 – Autumn term 2016**

Nursing students from the School of Healthcare Sciences, Cardiff, UK (Erasmus), Al Quds University, Jerusalem, Palestine (Linneus Palme), Zaragoza university Spain (Erasmus), Padua University Italy (Erasmus).

## **International research collaboration**

Collaboration with the research group at KU Leuven, Belgium. Professor Philip Moons. Collaborative project with the University of Capetown within the Adole7C project. Ongoing 2016-2020. Professor Liesl Zulcke.

## **Commissions by Queen Silvia Children's Hospital**

### **Clinical work on unit 323, pediatric cardiology**

Lead regular nursing rounds for nurses and pediatric nurses on unit 323. Conduct clinical work as a specialist nurse on the same unit within the parameters of this multistranded role.

### **Pediatric introduction year for newly graduated nurses**

Involved in the pediatric introduction course which is a specialist clinical training year within the Sahlgrenska framework aiming to achieve:

- Good quality, safe care through increased competence and patient safety in pediatric care
- Improved work environment for the individual nurse, contributing to reduced staff turnover and increasing attractiveness of the workplaces in this field
- Improved quality in line with the goal of being the leading university hospital in the country

### **Chief supervisor students in clinical training**

From 1st October 2010 to 28th February 2014 I was chief supervisor for clinical training (VFU) on the academic healthcare programmes. Queen Silvia Children's Hospital takes around 80-100 students per year from the academic healthcare programmes at basic and advanced level from Gothenburg University, University West, Trollhättan, University College Borås, University College Skövde, School of Health and Welfare, Jönköping and University College, Halmstad. This role included teaching and supervision of students and of supervisory nurses.

Chief supervisor role included:

- Supporting the student in achieving the goals of clinical training
- Developing good collaboration between operations and universities
- Developing clinical training
- Developing scientific anchoring

## **Contribution teaching materials**

Co-author of the chapter "Empowering young persons during the transition to adulthood" for the textbook, Transition from Pediatric to Adult Healthcare Services for Young Adults with Long-term Conditions: An International Perspective on Nurses' Roles and Interventions. 2019. Editors: Cecily Betz and Imelda Coyne.

## **Academic leadership**

See project management description of three ongoing projects.

## **Other leadership experiences**

### **Assigned by the Institute of Health and Care Sciences, Gothenburg University**

Member of the research committee (FOS). The committee advises Head of Department and provides a forum for dialogue and discussion about the institute's research.

### **Assigned by Queen Silvia Children's hospital, Östra sjukhuset.**

Member of FoU research committee, area 1.

Member of management team, pediatric cardiology, area 1.

Member of the board for the new pediatric hospital in Gothenburg 2012-2015.

## **Membership of national and international networks relevant to my research field**

- Nurses and allied health professions - AEPC (Association for European Paediatric Cardiology). [www.aepc.org](http://www.aepc.org).
- VIC (Care professions in Cardiology) – Congenital heart defects. [www.v-i-c.nu](http://www.v-i-c.nu)
- Sigma Theta Tau, Swedish Chapter; Tau Omega Chapter
- Cardiovascular Nursing and Allied professions (CCNAP)
- Riksföreningen för Barnsjuksköterskor (National association of pediatric nurses)

## **Public outreach**

1. Authored a literature review together with Carina Sparud-Lundin on behalf of the Swedish Agency for Health and Care Services Analysis. The literature review will be included in a report on the transition from children to adult health care for young people with long-term conditions, which the Swedish Agency for Health and Care Services Analysis will issue in the autumn of 2019. <https://www.vardanalys.se/in-english/>
2. Produced the film, *Skarven i vården* (The healthcare gap) with our research team to spread knowledge about our ongoing research. <https://youtu.be/ZRwGYdWtD3A>
3. Vetenskapsfestivalen (Swedish science festival) 27 April 2018. Lecture: Skarven i vården-överföring från barn till vuxensjukvård. Gothenburg.
4. Family screening for hypertrophic cardiomyopathy – presentation of doctoral project (Swedish) Hjärtebarnsförbundets förbundsrad 12 November 2011. Stockholm. Invited speaker.

Also see popular science publications.

## **Voluntary work**

1. Chair of the working group, “Nurses and Allied Professions” in AEPC (Association for European Paediatric Cardiology). [www.aepc.org](http://www.aepc.org). 2016-2019
2. Member of the working group, “Nurses and Allied Professions” in AEPC (Association for European Paediatric Cardiology). [www.aepc.org](http://www.aepc.org). 2020-2022
3. Member of the working group “Congenital heart defects” in VIC (Care professions in Cardiology) April 2010 – 2018 [www.v-i-c.nu](http://www.v-i-c.nu)
4. Editor of Barnbladet – magazine for Riksföreningen för barnsjuksköterskor (National association of pediatric nurses). January 2008 – Dec 2010.