

# The Asthma Multiverse Shared Decision Making in Pediatric Asthma Care

Joi Lucas, MD

Pediatric Pulmonology

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# Objectives

## Discuss

- Discuss methods for shared decision making in Pediatric asthma

## Review

- Review outcomes of shared decision making interventions for asthma

## Understand

- Understand barriers to effective shared decision making in Pediatric asthma management

## Review

- Review technology use with shared decision making

# Asthma Healthcare Burden

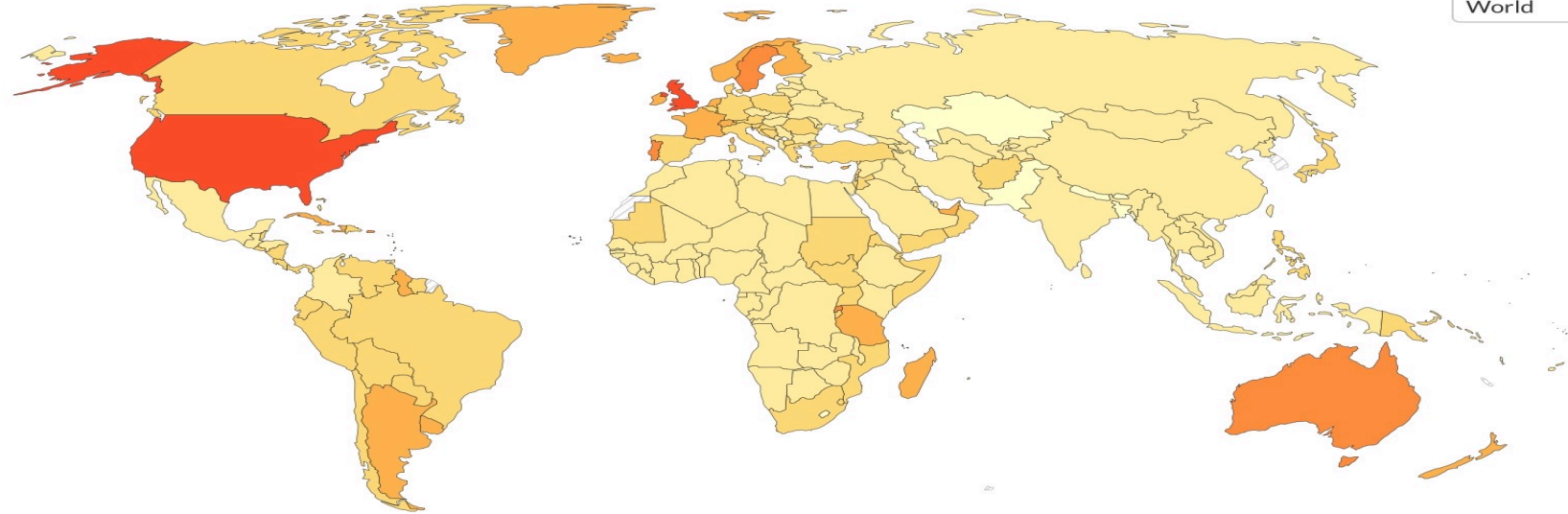


## Asthma prevalence, 2019

The share of the population with asthma. Prevalence is age-standardized so accounts for changes in the age structure of a population over time and between countries.

Our World  
in Data

World



Source: IHME, Global Burden of Disease (2019)

[OurWorldInData.org/burden-of-disease](https://OurWorldInData.org/burden-of-disease) • CC BY

▶ 1990

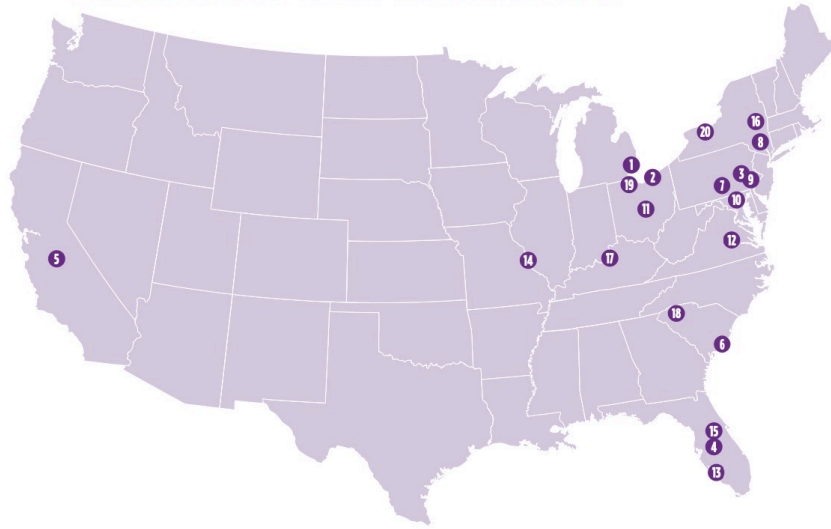
○ 2019

Global Burden of Disease Collaborative Network. Global Burden of Disease Study 2019 (GBD 2019) Results. Seattle, United States: Institute for Health Metrics and Evaluation (IHME), 2021.

Global Burden of Asthma



## Map of the Top 20 Most Challenging Places to Live With Asthma in 2022



These are the top 20 Asthma Capitals based on estimated asthma prevalence, emergency department visits due to asthma, and asthma-related fatalities. The burden of asthma falls heavily on the eastern half of the country, including some cities in the Midwest. The full list of top 100 cities can be found on [page 7](#) in this report.

- |                     |                    |
|---------------------|--------------------|
| 1. Detroit, MI      | 11. Columbus, OH   |
| 2. Cleveland, OH    | 12. Richmond, VA   |
| 3. Allentown, PA    | 13. Cape Coral, FL |
| 4. Lakeland, FL     | 14. St. Louis, MO  |
| 5. Fresno, CA       | 15. Orlando, FL    |
| 6. Charleston, SC   | 16. Albany, NY     |
| 7. Harrisburg, PA   | 17. Louisville, KY |
| 8. Poughkeepsie, NY | 18. Greenville, SC |
| 9. Philadelphia, PA | 19. Toledo, OH     |
| 10. Baltimore, MD   | 20. Rochester, NY  |

## AsthmaCAPITALS

The top 10 most challenging places to live with asthma are:

1. Detroit, Michigan
2. Cleveland, Ohio
3. Allentown, Pennsylvania
4. Lakeland, Florida
5. Fresno, California
6. Charleston, South Carolina
7. Harrisburg, Pennsylvania
8. Poughkeepsie, New York
9. Philadelphia, Pennsylvania
10. Baltimore, Maryland

## Black, Hispanic, and Indigenous individuals in the U.S. face THE HIGHEST BURDEN OF ASTHMA.

These disparities are caused by complex factors including systemic and structural racism.

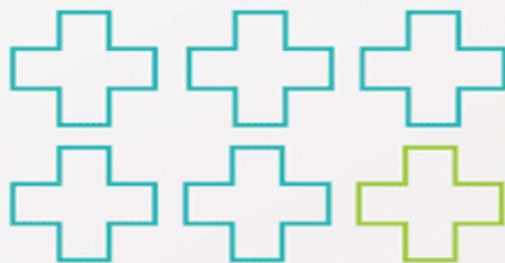
### Compared to white Americans:



Black Americans  
are nearly  
**1.5 times**  
more likely  
to have asthma



Puerto Rican  
Americans  
are nearly  
**2 times**  
more likely  
to have asthma



Black Americans  
are **5 times**  
more likely to visit  
the emergency  
department  
due to asthma



Black  
Americans  
are **3 times**  
more likely  
to die from  
asthma



When sex is  
factored in,  
**BLACK  
WOMEN**  
have the  
highest rates  
of death due  
to asthma

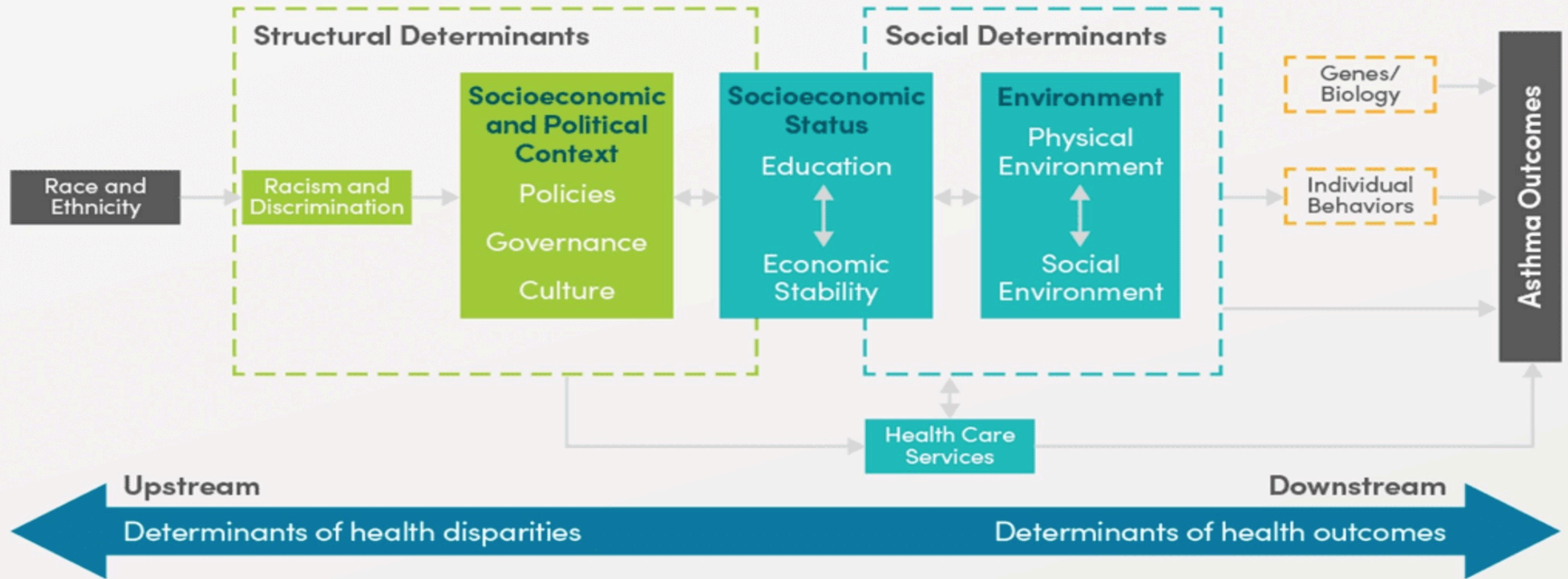


Asthma and Allergy  
Foundation of America

[aafa.org/asthmadisparities](https://aafa.org/asthmadisparities)



# AAFA'S FRAMEWORK FOR ROOT CAUSES OF ASTHMA DISPARITIES

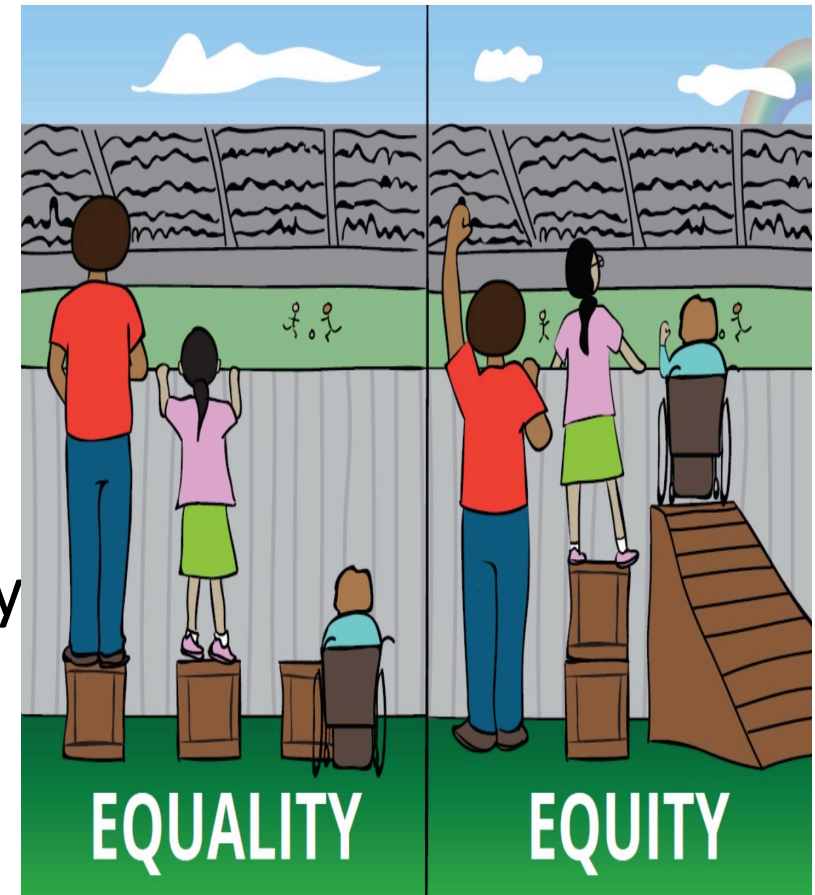


Asthma and Allergy  
Foundation of America

[aafa.org/asthmadisparities](https://aafa.org/asthmadisparities)

# What is a Health Disparity?

When a health condition affects one group of people differently than another group



# Pediatric Asthma

Asthma is the most common chronic childhood condition

1 in 12 children are affected in the United States

Black and Hispanic children are twice as likely to have asthma than White Children

Respiratory viruses such as human rhinovirus, respiratory syncytial virus, and influenza virus are common triggers for asthma exacerbations.

Leading causes of school absenteeism, with approximately 49% of school-aged children with asthma missing one or more school days per year



# Challenges in Asthma Management

On average, children and adults with asthma take 50% or less of their prescribed controller medications



## Common barriers to self-management:

Poor adherence to treatment

Incorrect use of rescue and controller medications

Misunderstanding of triggers and symptoms

# Treatment Adherence in Adolescents with Asthma

This article was published in the following Dove Press journal:  
*Journal of Asthma and Allergy*

Alan Kaplan<sup>1-3</sup>  
David Price<sup>3,4</sup>

<sup>1</sup>University of Toronto Department of Family and Community Medicine, Toronto, ON, Canada; <sup>2</sup>Family Physician Airways Group of Canada, Edmonton, AB, Canada; <sup>3</sup>Observational and Pragmatic Research Institute, Singapore, Singapore; <sup>4</sup>Centre of Academic Primary Care, Division of Applied Health Sciences, University of Aberdeen, Aberdeen, UK

**Abstract:** The burden of asthma is particularly notable in adolescents, and is associated with higher rates of prevalence and mortality compared with younger children. One factor contributing to inadequate asthma control in adolescents is poor treatment adherence, with many pediatric studies reporting mean adherence rates of 50% or lower. Identifying the reasons for poor disease control and adherence is essential in order to help improve patient quality of life. In this review, we explore the driving factors behind non-adherence in adolescents with asthma, consider their consequences and suggest possible solutions to ensure better disease control. We examine the impact of appropriate inhaler choice and good inhaler technique on adherence, as well as discuss the importance of selecting the right medication, including the possible role of as-needed inhaled corticosteroids/long-acting  $\beta_2$ -agonists vs short-acting  $\beta_2$ -agonists, for improving outcomes in patients with mild asthma and poor adherence. Effective patient/healthcare practitioner communication also has a significant role to engage and motivate adolescents to take their medication regularly.

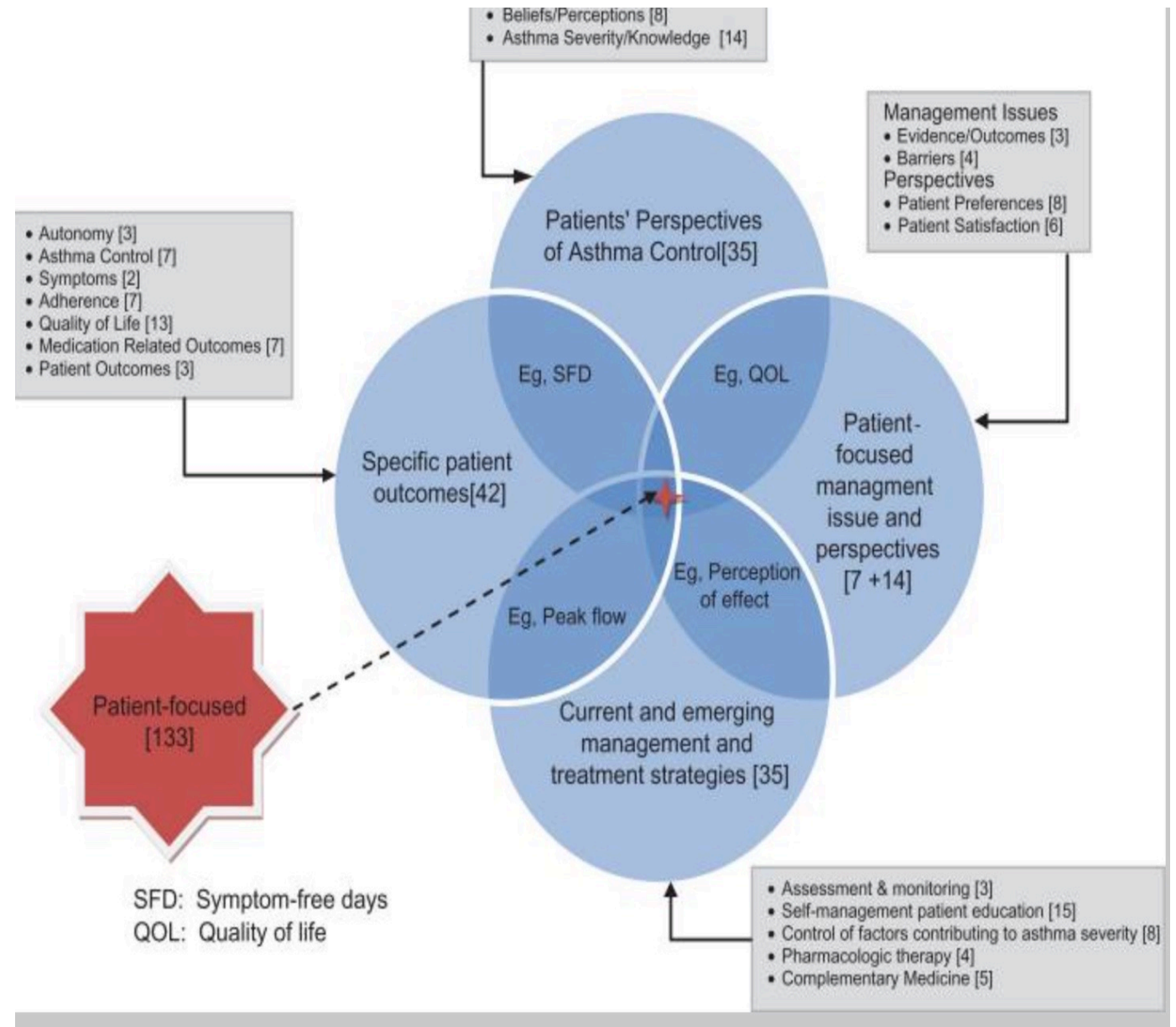
**Keywords:** asthma, adherence, adolescents, treatment

**Table 1** Factors Affecting Asthma Medication Non-Adherence

General Factors	Adolescent-Specific Factors
<ul style="list-style-type: none"> <li>• Inadequate instructions or complex/time-consuming regimen</li> </ul>	<ul style="list-style-type: none"> <li>• Desire for independence and responsibility, including rejection of parental monitoring and support</li> </ul>
<ul style="list-style-type: none"> <li>• Lack of structured home environment/routine, including hectic schedules</li> </ul>	<ul style="list-style-type: none"> <li>• Parent–child conflict and confusion over who is responsible for ensuring that medications are taken correctly</li> </ul>
<ul style="list-style-type: none"> <li>• Lack of communication/coordination between patients and caregivers</li> </ul>	<ul style="list-style-type: none"> <li>• Difficulties in organizing time and setting priorities</li> </ul>
<ul style="list-style-type: none"> <li>• Insufficient education and negative perceptions about treatment, eg, unpalatable taste, fear of side effects and concerns about addiction/dependence</li> </ul>	<ul style="list-style-type: none"> <li>• Forgetfulness or being too busy to take medication</li> </ul>
<ul style="list-style-type: none"> <li>• Incorrect inhaler use</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of engagement in decision-making around medication use</li> </ul>
<ul style="list-style-type: none"> <li>• Lack of awareness of difference between rescue and controller medication</li> </ul>	<ul style="list-style-type: none"> <li>• Overreliance on parents/caregivers coupled with lack of parental motivation, eg, due to emotional/financial burden or maternal depression</li> </ul>
<ul style="list-style-type: none"> <li>• Unwillingness to take medication to prevent or reduce future risks rather than to address immediate symptoms</li> </ul>	
<ul style="list-style-type: none"> <li>• Lack of trust or poor rapport between patients and HCPs</li> </ul>	<ul style="list-style-type: none"> <li>• Not being motivated to take medication or considering regimen to be too time-consuming or to conflict with other activities</li> </ul>
<ul style="list-style-type: none"> <li>• Inability to recognize asthma symptoms or tolerance of asthma symptoms that most HCPs would find unacceptable</li> </ul>	<ul style="list-style-type: none"> <li>• Lack of perceived effect of asthma medications</li> </ul>
<ul style="list-style-type: none"> <li>• Impact of mental health, eg, depression and anxiety</li> </ul>	<ul style="list-style-type: none"> <li>• Social stigma/embarrassment in front of friends</li> </ul>
	<ul style="list-style-type: none"> <li>• Risk-taking behaviors such as smoking, drinking alcohol and marijuana use</li> </ul>
	<ul style="list-style-type: none"> <li>• Increased impact of mental health disorders in adolescents</li> </ul>

**Abbreviation:** HCP, healthcare practitioner.

# Models in Asthma Care: Patient Centered Care





# What is Shared Decision Making?

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# Shared Decision Making- Multistep Process

Relationship building



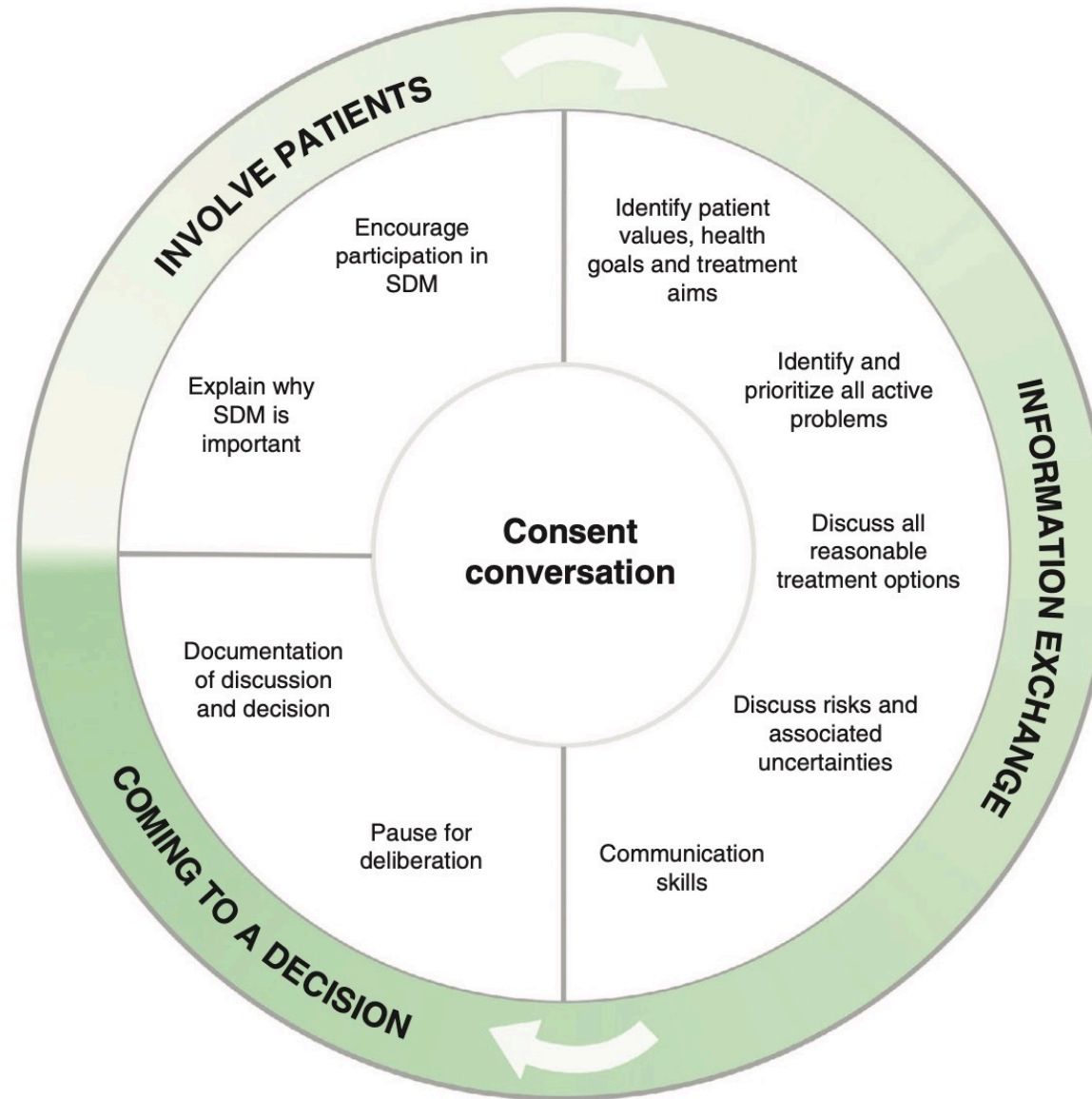
```
graph TD; A[Relationship building] --> B[Sharing of information]; B --> C[Patients can express preferred treatment or non-treatment];
```

The diagram illustrates a three-step process for shared decision making. It begins with a blue box labeled 'Relationship building', followed by a green box labeled 'Sharing of information', and finally a darker green box labeled 'Patients can express preferred treatment or non-treatment'. Downward-pointing arrows connect the boxes in sequence, indicating a linear progression.

Sharing of information

Patients can express preferred treatment or non-treatment

## How Do I Approach Shared Decision Making?



Normahani P, Sounderajah V, Harrop-Griffiths W, Chukwuemeka A, Peters NS, Standfield NJ, Collins M, Jaffer U. Achieving good-quality consent: review of literature, case law and guidance. *BJS Open*. 2020 Oct;4(5):757-763. doi: 10.1002/bjs5.50306. Epub 2020 May 31. PMID: 32475083; PMCID: PMC7528509.

# Pediatrics and Shared Decision Making

## Evolving developmental context

- Biological, cognitive, and psychosocial variables


## Multiple stakeholders

- Child, family, and health care provider

## Parents act as surrogate decision makers

## Legislation and policy about pediatric health decisions

- State/Provincial laws



## Effective Communication Strategies to Use with Children

Visual aids

Turn-taking

Eliciting attention/Requesting help

Clarifying communication with children

Role modeling

# Barriers To Shared Decision Making

## Providers



Time constraints



**Lack of applicability due to**

patient characteristics

clinical situation

inadequate knowledge

## Patient

- Power imbalances in the doctor-patient relationship
- Inadequate knowledge



# Benefits of Shared Decision Making

## Improvement

- asthma outcomes
- medication adherence
- patient and parent satisfaction
- quality of life

## Reduction of health care disparities

- Incorporate social, cultural, and environmental consideration leading to more inclusive, effective, and culturally appropriate care

# Is Shared Decision Making Effective?







Published in final edited form as:

*J Asthma*. 2018 June ; 55(6): 675–683. doi:10.1080/02770903.2017.1362423.

## Impact of Shared Decision Making on Asthma Quality of Life and Asthma Control among Children

Yhenneko J. Taylor, PhD<sup>a</sup>, Hazel Tapp, PhD<sup>a</sup>, Lindsay E. Shade, MHS, PA-C<sup>a</sup>, Tsai-Ling Liu, PhD<sup>a</sup>, Jessica Lauren Mowrer, BA<sup>a</sup>, Michael F. Dulin, MD PhD<sup>a,b</sup>

<sup>a</sup>Carolinas HealthCare System, Charlotte, North Carolina;

<sup>b</sup>University of North Carolina at Charlotte, Charlotte, North Carolina

### Abstract

**Objective:** Few studies have examined the effectiveness of shared decision making (SDM) in clinical practice. This study evaluated the impact of SDM on quality of life and symptom control in children with asthma.

**Methods:** We conducted a prospective 3-year study in six community-based practices serving a low-income patient population. Practices received training on SDM using an evidence-based toolkit. Patients aged 2 to 17 with a diagnosis of asthma were identified from scheduling and billing data. At approximate 6-month intervals, patients completed a survey consisting of the Mini Pediatric Asthma Quality of Life Questionnaire (range 1–7) and the control domain of the Pediatric Asthma Therapy Assessment Questionnaire (range 0–7). We used propensity scores to match 46 children receiving SDM to 46 children receiving usual care with decision support. Included children had completed a baseline survey and at least one follow-up survey. Random coefficient models incorporated repeated measures to assess the effect of SDM on asthma quality of life and asthma control.

**Results:** The sample was primarily of non-White patients (94.6%) with Medicaid insurance (92.4%). Receipt of SDM using an evidence-based toolkit was associated with higher asthma quality of life (mean difference 0.9; 95% confidence interval [CI] 0.4–1.4) and fewer asthma control problems (mean difference –0.9; 95% CI –1.6– –0.2) compared to usual care with decision support.

**Address correspondence to:** Yhenneko J. Taylor, PhD, Center for Outcomes Research and Evaluation, Carolinas HealthCare System, 1540 Garden Terrace, Suite 405, Charlotte, NC 28203, yhenneko.taylor@carolinashealthcare.org, Phone: 704-355-6562, Fax: 704-355-6077.

Contributors' Statement

Dr. Taylor developed the analysis plan, managed the study data, conducted initial statistical analyses, drafted the manuscript and approved the final manuscript as submitted.

Dr. Tapp and Ms. Shade assisted with conceptualization of the study, conducted training on shared decision making, assisted with interpretation of results and approved the final manuscript as submitted.

Dr. Liu conducted statistical analyses, critically reviewed the manuscript, and approved the final manuscript as submitted.

Ms. Mowrer coordinated the data collection, critically reviewed the manuscript, and approved the final manuscript as submitted.

Dr. Dulin conceptualized and designed the study, assisted with interpretation of results and approved the final manuscript as submitted. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Declaration of Interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Prospective 3 year study in 6 community based practices serving a low income patient population.

Patients 2-17 with a diagnosis of asthma

Quality of Life Survey given at 6 month intervals

Matched case and controls

- 46 children receiving SDM
- 46 children usual care and

Results- Shared decision making using evidence based toolkit

- Associated the higher asthma quality of life
- Fewer control problems



Published in final edited form as:

*J Asthma*. 2018 September ; 55(9): 949–955. doi:10.1080/02770903.2017.1378357.

## Shared decision making and time to exacerbation in children with asthma

Tsai-Ling Liu, PhD<sup>a</sup>, Yheneko J. Taylor, PhD<sup>a</sup>, Rohan Mahabaleshwarkar, PhD<sup>a</sup>, Christopher M. Blanchette, PhD<sup>b</sup>, Hazel Tapp, PhD<sup>c</sup>, Michael F. Dulin, MD, PhD<sup>b</sup>

<sup>a</sup>Center for Outcomes Research and Evaluation, Carolinas HealthCare System, Charlotte, NC, USA;

<sup>b</sup>Department of Public Health Sciences, University of North Carolina at Charlotte, Charlotte, NC, USA;

<sup>c</sup>Department of Family Medicine, Carolinas HealthCare System, Charlotte, NC, USA

### Abstract

**Objective:** Although shared decision making (SDM) is a promising approach for improving outcomes for patients with chronic diseases, no evidence currently supports the use of SDM to delay asthma exacerbations. We evaluated the impact of an SDM intervention implemented by providers in a real-world setting on time to exacerbation in children with asthma.

**Methods:** This study used a prospective cohort observed between 2011 and 2013 at five primary care practices that serve vulnerable populations (e.g., Medicaid and uninsured patients) in Charlotte, NC. Patients aged 2 to 17 receiving SDM were matched to those receiving usual care using propensity scores. Time to asthma exacerbation (asthma hospitalization, emergency department visit or oral steroid prescription in the outpatient setting) was compared between groups using Kaplan-Meier curves and conditional Cox proportional hazards models.

**Results:** The cohort included 746 children, 60.5% male and 54.2% African American, with a mean age of 8.6 years. Of these, 625 received usual care and 121 received SDM. The final analysis included 100 matched pairs of children. Kaplan-Meier curves showed longer exacerbation-free time for patients in the SDM intervention compared to those in usual care ( $p = 0.005$ ). The difference in risk of experiencing an exacerbation was marginally significant between the two groups (HR = 0.56, 95% C.I. = 0.29–1.08,  $p = 0.08$ ).

**Conclusions:** SDM was found to delay exacerbations among children with asthma. Clinicians should consider incorporating patient preferences in treatment decisions through SDM as a means for longer exacerbation-free time among children with poor asthma control.

**CONTACT** Tsai-Ling Liu, PhD Tsai-Ling.Liu@carolinashealthcare.org 1540 Garden Terrace, Suite 405, Charlotte, NC 28203, USA.

Declaration of interest

Dr Blanchette reports being employed and receiving consulting fee from Precision Health Economics, receiving consulting fee from Grifols and United Therapeutics, and receiving research fund as principal investigator at Teva Pharmaceuticals and Novartis Pharmaceuticals. Dr Dulin reports receiving consulting fee from Tresata. The authors alone are responsible for the content and writing of the paper.

Prospective cohort 2011-2013 based at 5 practices serving a low income patient population.

Patients 2-17 with a diagnosis of asthma

Time to asthma exacerbation  
(asthma hospitalization, ED visit, or oral steroid in outpatient setting)

100 Matched case and controls

- 50 children receiving SDM
- 50 children usual care

Results: Risk difference of experiencing an exacerbation was marginally significant.

Shared decision making delayed exacerbations among children with asthma

# Parent-Reported Outcomes of a Shared Decision-Making Portal in Asthma: A Practice-Based RCT

Alexander G. Fiks, MD, MScE<sup>1,2,3,4,5</sup>, Stephanie L. Mayne, MHS<sup>1,2</sup>, Dean J. Karavite, MSP<sup>1</sup>, Andrew Suh, BS<sup>1,2</sup>, Ryan O'Hara, BA<sup>1</sup>, A. Russell Localio, PhD<sup>1</sup>, Michelle Ross, PhD<sup>1</sup>, Robert W. Grundmeier, MD<sup>1,5,6</sup>

**BACKGROUND:** Electronic health record (EHR)-linked patient portals are a promising approach to facilitate shared decision-making between families of children with chronic conditions and pediatricians. This study evaluated the feasibility, acceptability, and impact of MyAsthma, an EHR-linked patient portal supporting shared decision-making for pediatric asthma.

**METHODS:** We conducted a 6-month randomized controlled trial of MyAsthma at 3 primary care practices. Families were randomized to MyAsthma, which tracks families' asthma treatment concerns and goals, children's asthma symptoms, medication side effects and adherence, and provides decision support, or to standard care. Outcomes included the feasibility and acceptability of MyAsthma for families, child health care utilization and asthma control, and the number of days of missed school (child) and work (parent). Descriptive statistics and longitudinal regression models assessed differences in outcomes between study arms.

**RESULTS:** We enrolled 60 families, 30 in each study arm (mean age 8.3 years); 57% of parents in the intervention group used MyAsthma during at least 5 of the 6 study months. Parents of children with moderate to severe persistent asthma used the portal more than others; 92% were satisfied with MyAsthma. Parents reported that use improved their communication with the office, ability to manage asthma, and awareness of the importance of ongoing attention to treatment. Parents in the intervention group reported that children had a lower frequency of asthma flares and intervention parents missed fewer days of work due to asthma.

**CONCLUSIONS:** Use of an EHR-linked asthma portal was feasible and acceptable to families and improved clinically meaningful outcomes.

## abstract



<sup>1</sup>The Pediatric Research Consortium, <sup>2</sup>Center for Biomedical Informatics, <sup>3</sup>PolicyLab, and <sup>4</sup>Center for Pediatric Clinical Effectiveness, The Children's Hospital of Philadelphia, Philadelphia, Pennsylvania; and <sup>5</sup>Departments of Pediatrics, and <sup>6</sup>Biostatistics and Epidemiology, Perelman School of Medicine, University of Pennsylvania, Philadelphia, Pennsylvania

Dr Fiks contributed to the conception and design of the study, acquisition of data, analysis and interpretation of the data, drafted the manuscript, and approved the final manuscript as submitted; Ms Mayne contributed to the acquisition of data, analysis and interpretation of data, drafting the manuscript, and approved the final manuscript as submitted; Mr Karavite, Mr Suh, and Mr O'Hara contributed to the acquisition of data, critically reviewed the manuscript, and approved the manuscript as submitted; Drs Localio, Ross, and Grundmeier contributed to the conception and design of the study, analysis and interpretation of data, critically reviewed the manuscript, and approved the final manuscript as submitted.

This trial has been registered at clinicaltrials.gov (identifier NCT01715389).

[www.pediatrics.org/cgi/doi/10.1542/peds.2014-3167](http://www.pediatrics.org/cgi/doi/10.1542/peds.2014-3167)

DOI: 10.1542/peds.2014-3167

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ARTICLE

TABLE 2

Asthma-Related Health Care Use Among Children in the Intervention and Control Groups Reported at 6-mo Follow-up

Type of Visit	Number and Proportion of Children With $\geq 1$ Event, <i>n</i> (%)		Total Count of Events	
	Intervention, <i>n</i> = 26	Control, <i>n</i> = 27	Intervention	Control
Hospitalizations	0 (0)	1 (4)	0	2
ED visits	2 (8)	6 (22)	3	9
Asthma specialist visits	8 (31)	12 (44)	11	21
Primary care asthma visits	16 (62)	18 (67)	29	41

Based on parent report. Twenty-six of 30 parents in the intervention group and 27 of 30 parents in the control group completed the 6-mo follow-up survey.



TABLE 3

Change in Days of School and Work Missed Because of Asthma

	Number and Proportion of Children/Parents Missing $\geq 1$ Day, <i>n</i> (%)				Mean Number of Days Missed per Child/Parent in Each Study Arm			
	Intervention	Control	DID	<i>P</i> <sup>a</sup>	Intervention	Control	DID	<i>P</i> <sup>b</sup>
Days of school missed in the past month (child)								
Baseline	14 (52)	16 (57)			1.7	2.3		
At 6 mo	7 (27)	11 (41)			0.6	1.9		
Change	−7 (−25)	−5 (−16)	−2 (−9)	.7	−1.1	−0.4	−0.7	.2*
Days of work missed in the past month (parent)								
Baseline	12 (46)	8 (32)			1.1	0.8		
At 6 mo	1 (4)	10 (37)			<0.1	1.5		
Change	−11 (−42)	+2 (+5)	−13 (−47)	.07	−1.1	+0.7	−1.8	.001*

At baseline, *n* = 30 for each group. At follow-up, *n* = 26 for intervention, *n* = 27 for control. DID, difference in difference.

<sup>a</sup>From longitudinal random intercept logit models (xtlogit in Stata) with a time\*study arm interaction, clustering by patient; *P* value is for the interaction term.

<sup>b</sup>From longitudinal random intercept negative binomial models (xtnbreg in Stata) with a time\*study arm interaction, clustering by patient; *P* value is for the interaction term.

The background is a dense, abstract composition of numerous 3D rectangular blocks or cubes. These blocks are arranged in a complex, layered pattern that creates a sense of depth and movement. The colors are varied, including shades of yellow, orange, red, brown, purple, blue, and green. The lighting appears to come from the upper left, casting shadows that emphasize the three-dimensional nature of the blocks. The overall effect is a vibrant, textured surface that resembles a digital or geometric landscape.

What is the Multiverse?



# The Asthma Multiverse





The background is a complex, abstract network of thin red lines connecting various points, creating a web-like structure. Scattered throughout this network are numerous 3D cubes of varying sizes and orientations. Some cubes are dark grey or black, while others are light grey or white. The overall color palette is dark, with the red lines providing a strong contrast. The lighting is soft, creating a sense of depth and highlighting the three-dimensional nature of the cubes.

# Technology and Shared Decision Making



## ORIGINAL ARTICLE



WILEY

# Artificial intelligence and the doctor–patient relationship expanding the paradigm of shared decision making

Giorgia Lorenzini<sup>1</sup> | Laura Arbelaez Ossa<sup>1</sup> | David Martin Shaw<sup>1,2</sup> | Bernice Simone Elger<sup>1,3</sup>

<sup>1</sup>Institute for Biomedical Ethics, University of Basel, Basel, Switzerland

<sup>2</sup>Care and Public Health Research Institute, Universiteit Maastricht, Maastricht, The Netherlands

<sup>3</sup>Center for Legal Medicine, Unit for Health Law and Humanitarian Medicine, University of Geneva, Geneva, Switzerland

## Correspondence

Giorgia Lorenzini, Institute for Biomedical Ethics, University of Basel, Bernoullistrasse 28, Basel 4056, Switzerland.

Email: [giorgia.lorenzini@unibas.ch](mailto:giorgia.lorenzini@unibas.ch)

## Funding information

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## Abstract

Artificial intelligence (AI) based clinical decision support systems (CDSS) are becoming ever more widespread in healthcare and could play an important role in diagnostic and treatment processes. For this reason, AI-based CDSS has an impact on the doctor–patient relationship, shaping their decisions with its suggestions. We may be on the verge of a paradigm shift, where the doctor–patient relationship is no longer a dual relationship, but a triad. This paper analyses the role of AI-based CDSS for shared decision-making to better comprehend its promises and associated ethical issues. Moreover, it investigates how certain AI implementations may instead foster the inappropriate paradigm of paternalism. Understanding how AI relates to doctors and influences doctor–patient communication is essential to promote more ethical medical practice. Both doctors' and patients' autonomy need to be considered in the light of AI.

# Artificial Intelligence (AI) and Shared Decision Making: A Paradigm Shift

Effective Communication + Respect for Voluntary Choices = Shared Decision Making

## AI Benefits

- Enhance diagnostic ability
- Empower decision making

## AI Risks

- Limiting autonomy (Double Paternalism)
  - Creating paternalistic doctor-patient relationship
  - AI may limit doctor's decisions
- Create additional obligations
- Lacks contextual and emotional intelligence

## RESEARCH ARTICLE

# Artificial intelligence-assisted clinical decision support for childhood asthma management: A randomized clinical trial

Hee Yun Seol<sup>1,2</sup>✉, Pragya Shrestha<sup>1,3</sup>✉, Joy Fladager Muth<sup>3</sup>, Chung-II Wi<sup>1,3</sup>, Sunghwan Sohn<sup>4</sup>, Euijung Ryu<sup>5</sup>, Miguel Park<sup>6</sup>, Kathy Ihrke<sup>1,3</sup>, Sungrim Moon<sup>4</sup>, Katherine King<sup>5</sup>, Philip Wheeler<sup>1</sup>, Bijan Borah<sup>7</sup>, James Moriarty<sup>8</sup>, Jordan Rosedahl<sup>8</sup>, Hongfang Liu<sup>4</sup>, Deborah B. McWilliams<sup>3</sup>, Young J. Juhn<sup>1,3</sup>\*

**1** Precision Population Science Lab, Mayo Clinic, Rochester, Minnesota, United States of America, **2** Department of Internal Medicine, Pusan National University Yangsan Hospital, Yangsan, Korea, **3** Department of Pediatric and Adolescent Medicine, Mayo Clinic, Rochester, Minnesota, United States of America, **4** Department of Artificial Intelligence and Informatics, Mayo Clinic, Rochester, Minnesota, United States of America, **5** Division of Biomedical Statistics and Informatics, Mayo Clinic, Rochester, Minnesota, United States of America, **6** Division of Allergic Diseases, Mayo Clinic, Rochester, Minnesota, United States of America, **7** Department of Health Service Research, Mayo Clinic, Rochester, Minnesota, United States of America, **8** Kern Center for the Science of Health Care Delivery, Mayo Clinic, Rochester, Minnesota, United States of America

✉ These authors contributed equally to this work.

\* [juhn.young@mayo.edu](mailto:juhn.young@mayo.edu)



## OPEN ACCESS

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**Data Availability Statement:** If any investigators at other academic institutions who wish to obtain the de-identified minimal data set used in the publication request access from the authors and Mayo directly, we can ensure the appropriate IRB approval and agreement is put into place to share the data. This process will ensure that they retain control of the data in accordance with Mayo policy. The appropriate contact person is Ms. Julie A. Hanson at Mayo Clinic ([Hanson.Julie1@mayo.edu](mailto:Hanson.Julie1@mayo.edu)).

## Abstract

### Rationale

Clinical decision support (CDS) tools leveraging electronic health records (EHRs) have been an approach for addressing challenges in asthma care but remain under-studied through clinical trials.

### Objectives

To assess the effectiveness and efficiency of Asthma-Guidance and Prediction System (A-GPS), an Artificial Intelligence (AI)-assisted CDS tool, in optimizing asthma management through a randomized clinical trial (RCT).

### Methods

This was a single-center pragmatic RCT with a stratified randomization design conducted for one year in the primary care pediatric practice of the Mayo Clinic, MN. Children (<18 years) diagnosed with asthma receiving care at the study site were enrolled along with their 42 primary care providers. Study subjects were stratified into three strata (based on asthma severity, asthma care status, and asthma diagnosis) and were blinded to the assigned groups.

### Measurements

Intervention was a quarterly A-GPS report to clinicians including relevant clinical information for asthma management from EHRs and machine learning-based prediction for risk of



# A-GPS reduced clinician burden for chart review

**Table 2. Primary and secondary outcomes in intervention and control groups.**

	<b>Intervention (n = 90)</b>	<b>Control (n = 94)</b>	<b>P-value</b>
Primary outcome			
Asthma exacerbation, n (%)	11 (12%)	14 (15%)	0.60
Secondary outcomes**			
Clinician's time in minutes taken to make clinical decision, median (IQR)	3.5 (2–5) min	11.3 (6.3–15) min	<0.001
Health care cost (\$), mean (95% CI)**			
Pre-intervention predicted cost	\$2474 (\$1540, \$3409)	\$1721 (\$1085, \$2357)	
Post-intervention predicted cost	\$1438 (\$895, \$1981)	\$1800 (\$1135, \$2466)	
Difference	-\$1036 (-\$2177, \$44)	\$80 (-\$841, \$1000)	0.12
Percentage of the duration of well-controlled asthma by quarterly ACT or TRACK score (%), median (IQR)	100 (75 to 10)	100 (100 to 100)	0.56
Timeliness for follow-up care after asthma exacerbation (days)^, median (IQR)	7 (2 to 27)	28 (6 to 48)	0.10

^Using Kapan Meier method among those with asthma exacerbation (11 for the Intervention and 14 for the control group)

\*\*Clinician's time for making clinical decision related to asthma for the intervention vs. the control group was compared, while clinicians themselves were not randomized.



# Digital Twin System for Children: Artificial Intelligence

JOURNAL OF MEDICAL INTERNET RESEARCH

Drummond & Coulet

## Viewpoint

## Technical, Ethical, Legal, and Societal Challenges With Digital Twin Systems for the Management of Chronic Diseases in Children and Young People

David Drummond<sup>1,2,3</sup>, MD, PhD; Adrien Coulet<sup>2,4</sup>, PhD

<sup>1</sup>Department of Paediatric Pulmonology and Allergology, University Hospital Necker-Enfants Malades, AP-HP, Paris, France

<sup>2</sup>Heka Team, Centre de Recherche des Cordeliers, Inserm, Université Paris Cité, Paris, France

<sup>3</sup>Centre for Health Informatics, University of Manchester, Manchester, United Kingdom

<sup>4</sup>Inria Paris Research Centre, Paris, France

### Corresponding Author:

David Drummond, MD, PhD

Department of Paediatric Pulmonology and Allergology

University Hospital Necker-Enfants Malades, AP-HP

149 rue de Sèvres

Paris, 75015

France

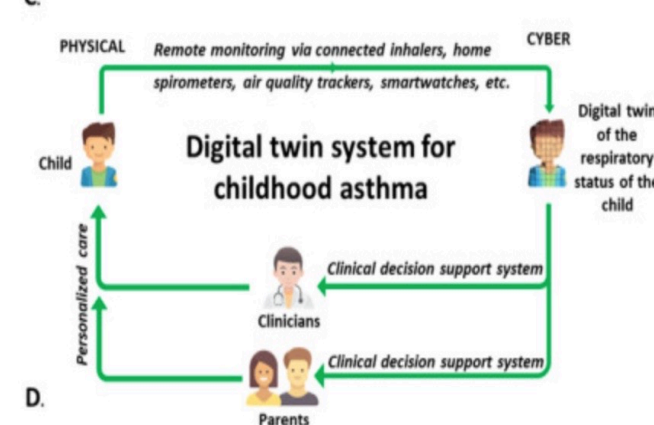
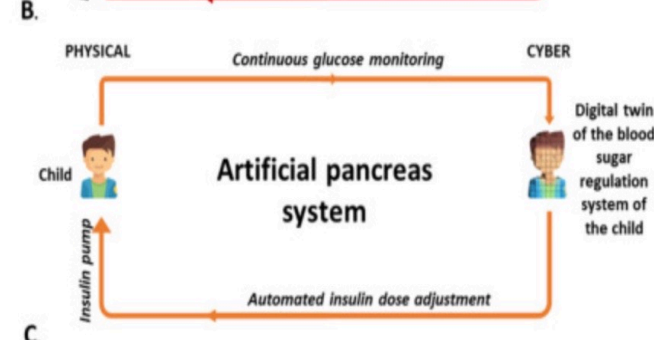
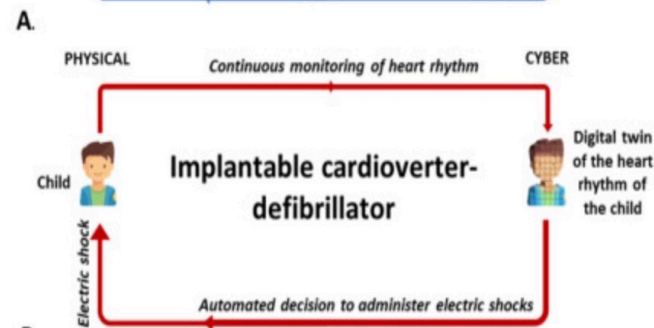
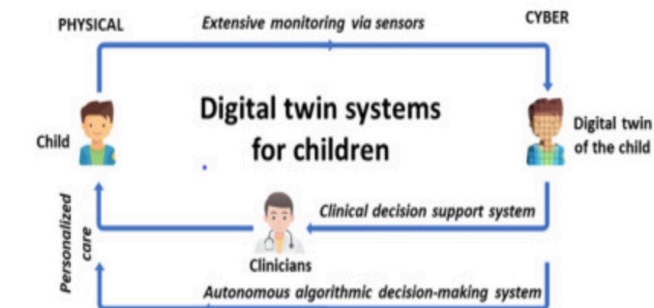
Phone: 33 144494848

Email: [david.drummond@aphp.fr](mailto:david.drummond@aphp.fr)

## Abstract

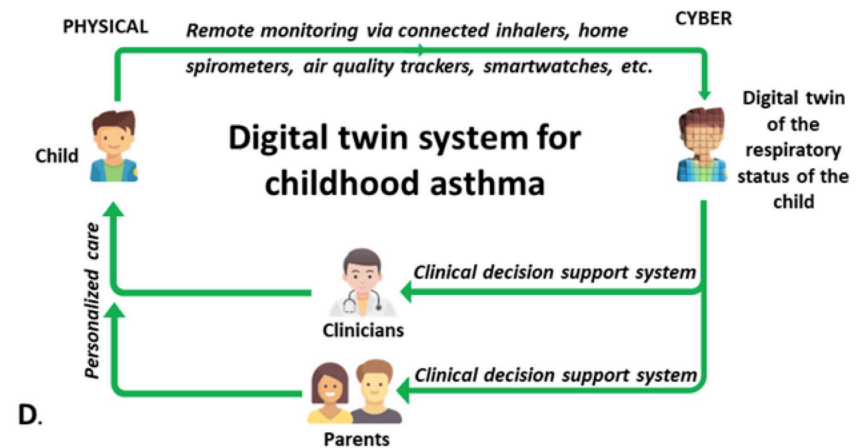
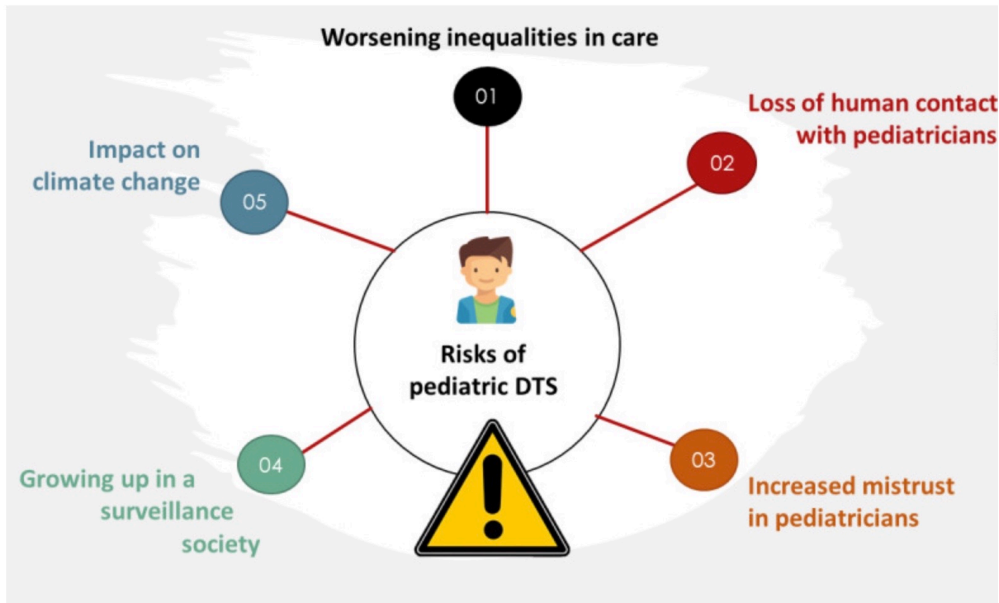
Advances in digital medicine now make it possible to use digital twin systems (DTS), which combine (1) extensive patient monitoring through the use of multiple sensors and (2) personalized adaptation of patient care through the use of software. After the artificial pancreas system already operational in children with type 1 diabetes, new DTS could be developed for real-time monitoring and management of children with chronic diseases. Just as providing care for children is a specific discipline—because of their particular characteristics and needs, providing digital care for children also presents particular challenges. This article reviews the technical challenges, mainly related to the problem of data collection in children; the ethical challenges, including the need to preserve the child's place in their care when using DTS; the legal challenges and the dual need to guarantee the safety of DTS for children and to ensure their access to DTS; and the societal challenges, including the needs to maintain human contact and trust between the child and the pediatrician and to limit DTS to specific uses to avoid contributing to a surveillance society and, at another level, to climate change.

(J Med Internet Res 2022;24(10):e39698) doi: [10.2196/39698](https://doi.org/10.2196/39698)



# Digital Twin System for Children: Artificial Intelligence

Figure 3



# Artificial Intelligence and Shared Decision Making in Children

European Journal of Pediatrics (2023) 182:877–888  
<https://doi.org/10.1007/s00431-022-04754-8>

## RESEARCH



## Children's views on artificial intelligence and digital twins for the daily management of their asthma: a mixed-method study

Apolline Gonsard<sup>1</sup> · Rola AbouTaam<sup>1</sup> · Blandine Prévost<sup>2</sup> · Charlotte Roy<sup>1</sup> · Alice Hadchouel<sup>1,3</sup> · Nadia Nathan<sup>2</sup> · Jessica Taytard<sup>2,4</sup> · Alexandra Pirojoc<sup>5</sup> · Christophe Delacourt<sup>1,3</sup> · Stéphanie Wanin<sup>6</sup> · David Drummond<sup>1,3,7</sup> 

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### Abstract

New technologies enable the creation of digital twin systems (DTS) combining continuous data collection from children's home and artificial intelligence (AI)-based recommendations to adapt their care in real time. The objective was to assess whether children and adolescents with asthma would be ready to use such DTS. A mixed-method study was conducted with 104 asthma patients aged 8 to 17 years. The potential advantages and disadvantages associated with AI and the use of DTS were collected in semi-structured interviews. Children were then asked whether they would agree to use a DTS for the daily management of their asthma. The strength of their decision was assessed as well as the factors determining their choice. The main advantages of DTS identified by children were the possibility to be (i) supported in managing their asthma (ii) from home and (iii) in real time. Technical issues and the risk of loss of humanity were the main drawbacks reported. Half of the children (56%) were willing to use a DTS for the daily management of their asthma if it was as effective as current care, and up to 93% if it was more effective. Those with the best computer skills were more likely to choose the DTS, while those who placed a high value on the physician–patient relationship were less likely to do so.

**Conclusions:** The majority of children were ready to use a DTS for the management of their asthma, particularly if it was more effective than current care. The results of this study support the development of DTS for childhood asthma and the evaluation of their effectiveness in clinical trials.

### What is Known:

- New technologies enable the creation of digital twin systems (DTS) for children with asthma.
- Acceptance of these DTSs by children with asthma is unknown.

### What is New:

- Half of the children (56%) were willing to use a DTS for the daily management of their asthma if it was as effective as current care, and up to 93% if it was more effective.
- Children identified the ability to be supported from home and in real time as the main benefits of DTS.



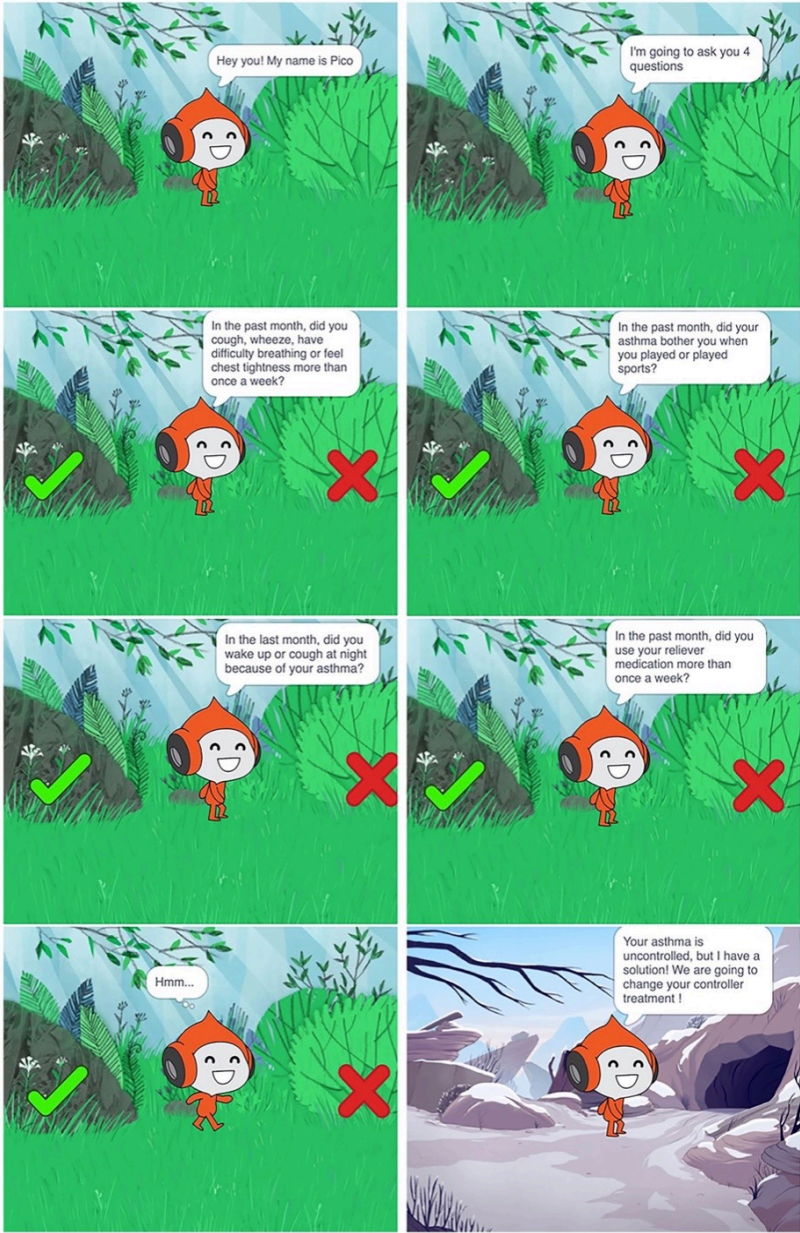


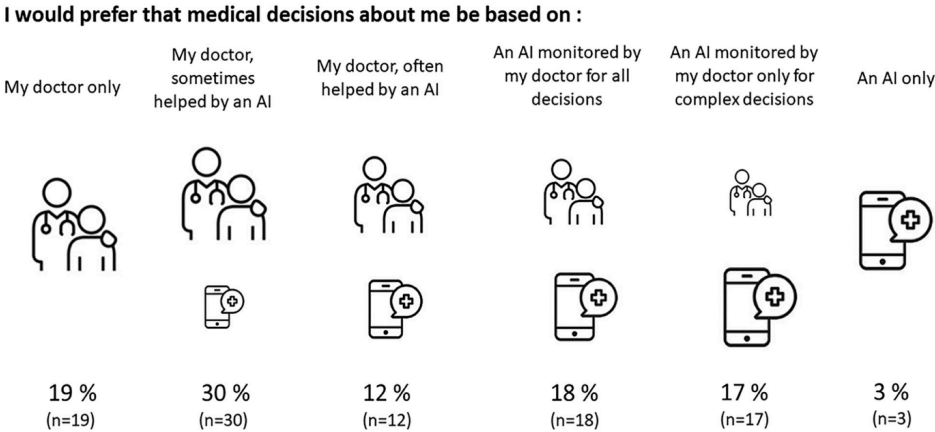
Fig. 1 Animation created for the study to show children what the interface of the digital twin system might look like (<https://scratch.mit.edu/projects/721368471>)

Table 4 Analysis of factors associated with acceptance of a DTS by children

Variable	Adjusted for	Odds ratio	Confidence interval
Age		1.03	0.91–1.17
Sex (male)		1.56	0.76–3.25
School level	Age, parent’s education level		
Elementary school		1 (ref)	Reference
Middle school		1.13	0.32–4.06
High school		1.21	0.16–9.95
Parent’s education level			
No degree		1 (ref)	Reference
High school degree		0.42	0.14–1.21
Undergraduate and graduate degree		1.05	0.30–2.81
Agreement to the use of personal data	Age, sex, computer skills, AI knowledge, parent’s academic level	1.19	0.80–1.78
Asthma severity (GINA Step)	Age, sex		
Step 1 (reference)		1 (ref)	Reference
Step 2 and 3		1.88	0.77–4.60
Step 4 and 5		2.10	0.73–6.16
Importance of the physician–patient relationship	Age, sex	0.82	0.68–0.98
Computer skills	Age, sex, school level Parent’s academic level,	2.01	1.26–3.27
Knowledge of AI	Age, sex, computer skills, Agreement about the use of personal data, parent’s academic level	1.40	0.93–2.13

AI artificial intelligence

Fig. 3 Children’s views on the place of the doctor and artificial intelligence in medical decisions about themselves. AI artificial intelligence





## Potential benefits

- **Improved health**
  - Increased autonomy in life (new activities allowed)
  - Improved mental well-being (decreased cognitive load)
  - Improved social development (engagement in new social activities)
  - Increased participation in sports (decreased symptoms during exercise)
- **Improved access to health care**
  - Remote disease management
  - Timely treatment adaptation
  - Standardization of the level of care



## Potential threats

- **Decreased health**
  - Risk of toxic exposure, choking (hardware)
  - Risk of malfunction (software)
- **Decreased autonomy in care**
  - Decreased participation in symptom description (child's PROM ignored)
  - Decreased participation in daily management (complexity)
- **Decreased well-being**
  - Decreased engagement in recreation and sports (complexity)
  - Reduced participation in social activities (shame and/or complexity of devices)
- **Exclusion of health care**
  - Not affordable
  - Not usable by families with low levels of digital literacy
  - Self-exclusion of low-income families (no trust in AI)

# Emerging Trends in Pediatric Asthma: Digital Health Interventions

## Digital health interventions in children with asthma

Giuliana Ferrante<sup>1</sup>  | Amelia Licari<sup>2</sup>  | Gian Luigi Marseglia<sup>2</sup>  | Stefania La Grutta<sup>3</sup> 

<sup>1</sup>Department of Health Promotion, Mother and Child Care, Internal Medicine and Medical Specialties, University of Palermo, Palermo, Italy

<sup>2</sup>Department of Pediatrics, Fondazione IRCCS Policlinico San Matteo, University of Pavia, Pavia, Italy

<sup>3</sup>Institute for Research and Biomedical Innovation (IRIB), National Research Council (CNR), Palermo, Italy

### Correspondence

Amelia Licari, Department of Pediatrics, Fondazione IRCCS Policlinico San Matteo, University of Pavia, viale Golgi 19, 27100 Pavia, Italy.  
Email: amelia.licari@unipv.it

### Abstract

Although healthcare providers are actively involved in offering education, information and interventions for asthmatic patients, medication and therapeutic adherence remain low in the paediatric population, with estimates suggesting that adherence rates hover below 50%. A range of available digital health interventions has been explored in paediatric asthma with promising but variable results, limiting their widespread adoption in clinical practice. They include emerging technologies that yield the advantage of tracking asthma symptoms and medications, setting drug reminders, improving inhaler technique and delivering asthma education, such as serious games (video games designed for medical- or health-related purposes), electronic monitoring devices, speech recognition calls, text messaging, mobile apps and interactive websites. Some of the proposed digital interventions have used multiple components, including educational and behavioural strategies and interactions with medical professionals. Overall, the implementation of such interventions may offer the opportunity to improve adherence and asthma control. In a state of emergency as the COVID-19 pandemic, telemedicine can also play a central role in supporting physicians in managing children with asthma. This review evaluates the published literature examining digital health interventions for paediatric asthma and explores the most relevant issues affecting their implementation in practice and the associated evidence gaps, research limitations and future research perspectives.

### KEYWORDS

adherence, asthma, children, control, digital health, intervention, serious games, telemedicine

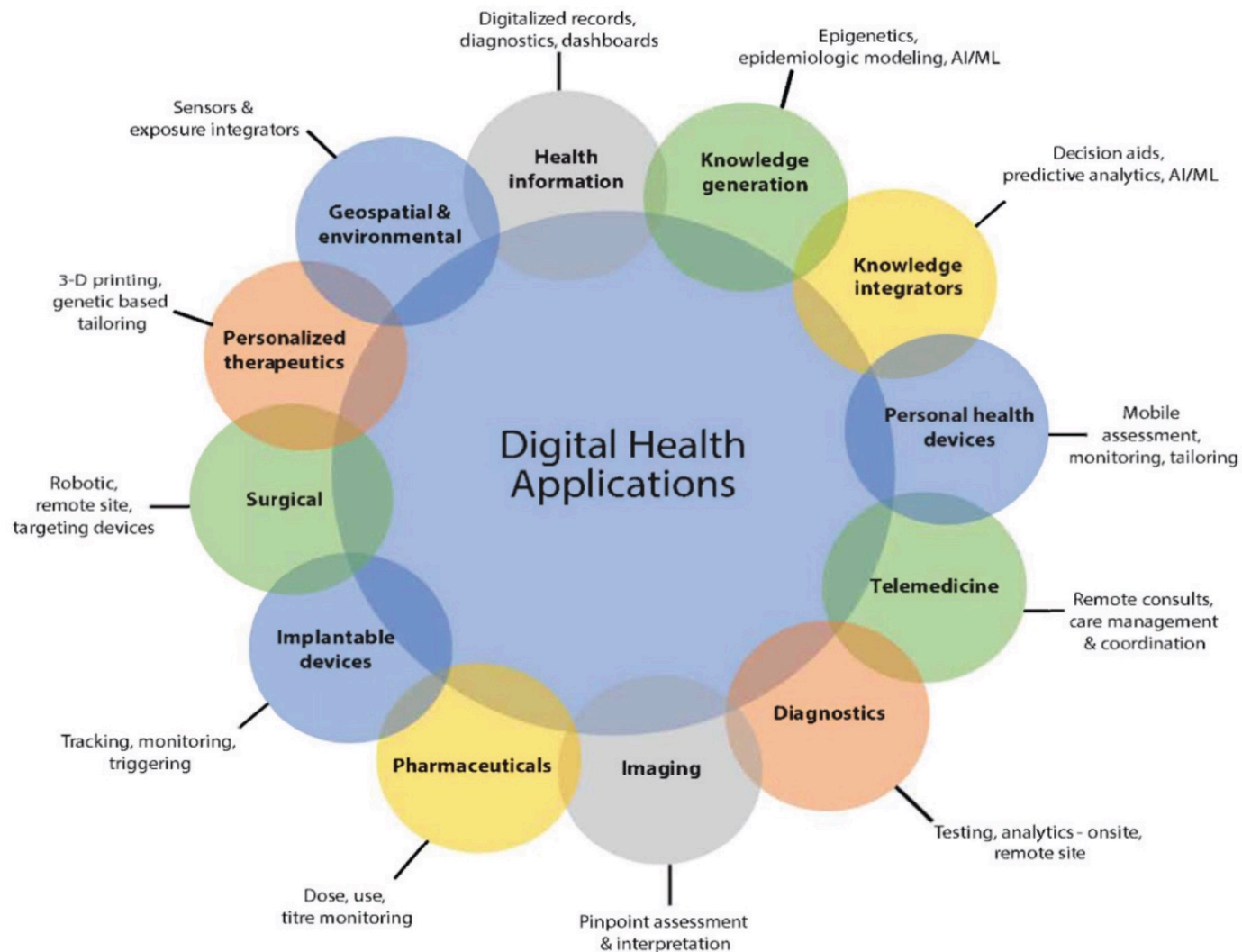
## 1 | INTRODUCTION

Asthma is a common chronic disease in childhood, affecting approximately 10% of children worldwide.<sup>1</sup> The management of the disease is primarily aimed at maintaining symptoms control and reducing the risk of exacerbations.<sup>2</sup> Although most children achieve good control with standard therapies, such as inhaled corticosteroids (ICS) and/or one or more controllers, asthma still imposes a high burden, especially in children with uncontrolled symptoms.<sup>3,4</sup> A major cause of uncontrolled asthma is poor adherence to treatment, which has

been described in 49%–71% of paediatric patients, resulting in an increased risk of missed days of school, decline in lung function, emergency department visits, hospitalizations and even death.<sup>5–10</sup> Therefore, it is important to take into account treatment adherence, inhaler technique and self-management education in the management of children with asthma. However, asthma management can be hampered by several factors related to individual, family, community, healthcare system and patient-provider interaction domains.<sup>11</sup>

Identifying interventions for promoting asthma treatment adherence and self-management is essential to obtain and maintain

Giuliana Ferrante and Amelia Licari are equally contributing co-first authors.



**FIGURE 1 | Evolving Applications of Digital Technology in Health and Health Care**

**SOURCE:** National Academy of Medicine. 2019. *Digital Health Action Collaborative, NAM Leadership Consortium: Collaboration for a Value & Science-Driven Health System.*



# Digital Health Interventions

- Serious Games
- Electronic Monitoring Devices
  - Measure time and date of drug actuations
    - Smartinhalers
- Tools for self monitoring symptoms
  - Asthma symptom tracker
  - Medication reminder
- Mobile Health
  - over 500 asthma apps





# Shared Decision Making and Social Media







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# Do Your Patients Listen to Asthma Advice from Social Media?

## ORIGINAL RESEARCH



# Describing the Digital Footprints or “Sociomes” of Asthma for Stakeholder Groups on Twitter

Christopher L. Carroll<sup>1</sup>, Viren Kaul<sup>2</sup>, Kathleen A. Sala<sup>1</sup>, and Neha S. Dangayach<sup>3</sup>

<sup>1</sup>Connecticut Children’s, Hartford, Connecticut; <sup>2</sup>Crouse Health, SUNY Upstate Medical University, Syracuse, New York; and <sup>3</sup>Icahn School of Medicine at Mount Sinai, New York, New York

## ABSTRACT

**Background:** Although there is a great deal of conversation on social media, there may not be good communication.

**Objective:** We sought to investigate communication activity online by examining digital footprints (or “sociomes”) of asthma stakeholders on Twitter.

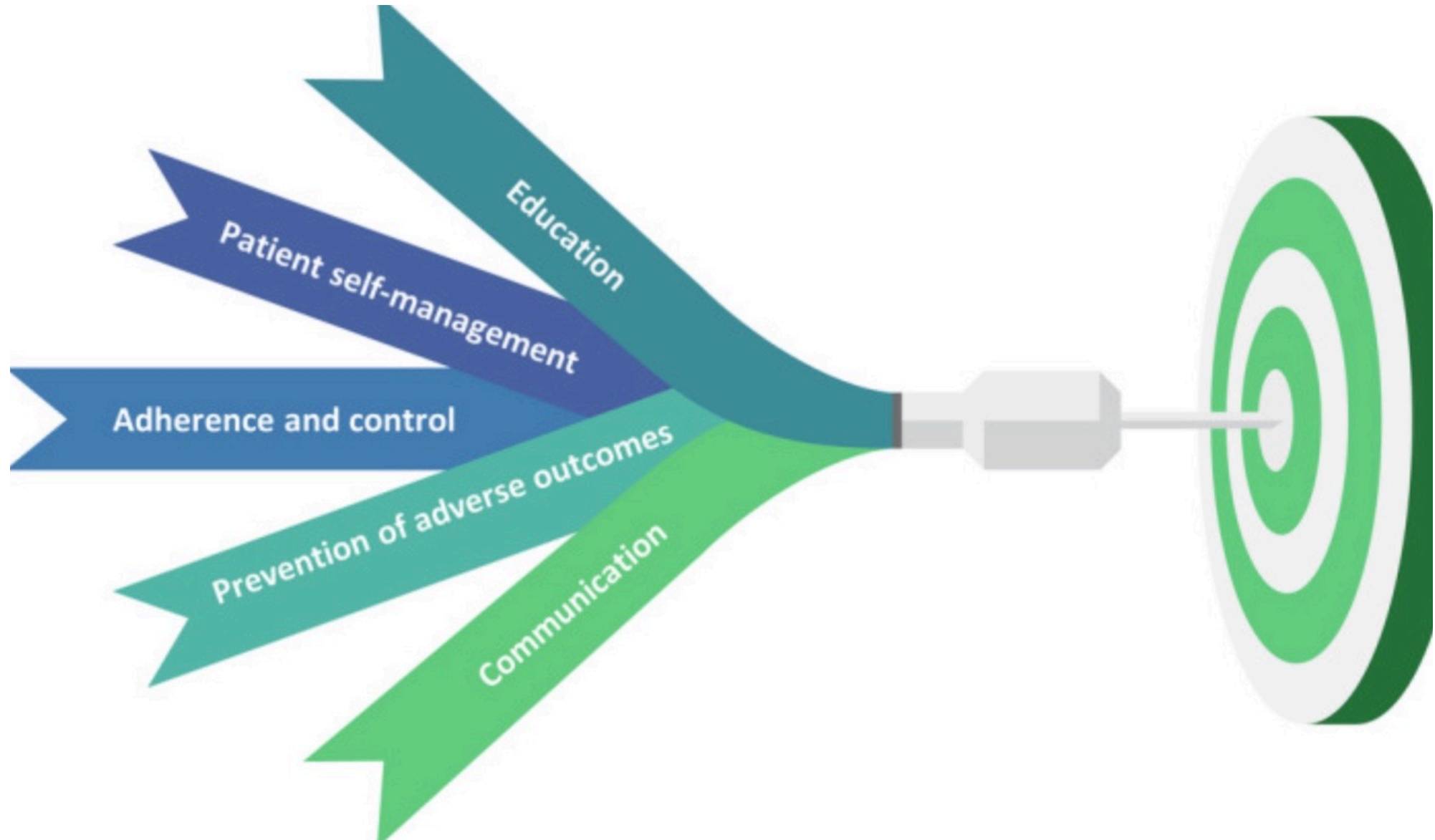
**Methods:** Tweets containing the word “asthma” and the hashtag #asthma were collected using Symplur Signals. Characteristics of usage and tweets were analyzed and compared first between the word “asthma” and the hashtag #asthma, and then among four different stakeholder groups: clinicians, patients, healthcare organizations, and industry.

**Results:** The #asthma sociome was significantly smaller than the “asthma” sociome, with fewer users and tweets per month. However, the #asthma sociome correlated better to asthma seasons and was less susceptible to vulgarity and viral memes. For the #asthma sociome, there were 695,980 tweets by 308,370 users between April 2015 and November 2018. Clinicians were responsible for 16% of tweets, patients 9%, healthcare organizations 22%, and industry 0.3%. There were significant differences in the tweet characteristics, with healthcare organizations more likely to tweet with links, clinicians more likely to mention other users, and industry more likely to use visuals. Each April–May, there were significant spikes in the frequency of tweets by patients, healthcare organizations, and industry, whereas the usage patterns of clinicians were more random. There were also differences in the top terms and hashtags tweeted with #asthma in the stakeholder groups.

**Conclusion:** Asthma stakeholder groups tweet differently, at different times, and use different associated terms. Further exploration may help improve health care–related communication and help guide education of patients and clinicians.



# Shared Decision Making



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