

Digital Health and Quality of Life Assessment in Hematology

Prof. Fabio Efficace

*Head, Health Outcomes Research Unit
Gruppo Italiano Malattie Ematologiche dell' Adulto (GIMEMA)
GIMEMA Data Center, Rome, Italy*

*Adjunct Professor, Feinberg School of Medicine,
Northwestern University, Chicago, USA*

 **fondazione GIMEMA** onlus
per la promozione e lo sviluppo della ricerca scientifica
sulle malattie ematologiche. **FRANCO MANDELLI**

Si ringrazia per il supporto



Con il patrocinio di

LE CURE PALLIATIVE PRECOCI IN
EMATO-ONCOLOGIA:
la nuova risposta ai bisogni di pazienti e caregivers

19 maggio 2023

Roma, Hotel Donna Camilla Savelli



Disclosures:

Consultancy/Advisory Board: AbbVie, Incyte, Syros, Janssen





Year 2002

Detmar SB, et al JAMA, 288:3027-3034, 2002

The importance of Quality of Life (QoL) monitoring in routine practice

Results The HRQL-related issues were discussed significantly more frequently in the intervention than in the control group (mean [SD] communication composite scores: 4.5 [2.3] vs 3.7 [1.9], respectively ($P=.01$). Physicians in the intervention group identified a greater percentage of patients with moderate-to-severe health problems in several HRQL domains than did those in the control group. All physicians and 87% of the patients believed that the intervention facilitated communication and expressed interest in its continued use.

Conclusion Incorporating standardized HRQL assessments in daily clinical oncology practice facilitates the discussion of HRQL issues and can heighten physicians' awareness of their patients' HRQL.

JAMA. 2002;288:3027-3034

www.jama.com



After 20 years of research...

Advantages of assessing Quality of Life (QoL) in Routine Cancer Practice

- **Facilitate and improve communication between patients and physicians**
- **Facilitate shared-decision making**
- **Enhance patient satisfaction**
- **Improve symptom control**
- **Improve Quality of Life**
- **Improve Survival Outcomes**

(Basch E, et al, J Clin Oncol. 34:557-65, 2016; Bennet AV et al., CA Cancer J Clin 62:336-347, 2012; Kotronoulas G, et al, J Clin Oncol, 32:1480–1501, 2014; Snyder C, et al, Qual Life res 21:1305-1314, 2012; Frost MH, Mayo Clin Proc, 82:1214–1228, 2007; Velikova G, et al, J Clin Oncol, 22:714–724, 2004; McLachlan SA, et al, J Clin Oncol, 19:4117–4125, 2001; Detmar SB, et al, Eur J Cancer, 34:1181–1186, 1998; Denis F. et al. J Natl cancer Inst 109(9), 2017; Basch E, et al . Am Soc Clin Oncol Educ Book. 2018 May 23;38:122-134)



Web-based Symptom Monitoring in Routine Cancer Treatment improves Survival

JOURNAL OF CLINICAL ONCOLOGY

ORIGINAL REPORT

Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial

Ethan Basch, Allison M. Deal, Mark G. Kris, Howard I. Scher, Clifford A. Hudis, Paul Sabbatini, Lauren Rogak, Antonia V. Bennett, Amylou C. Dueck, Thomas M. Atkinson, Joanne F. Chou, Dorothy Dulko, Laura Sit, Allison Barz, Paul Novotny, Michael Fruscione, Jeff A. Sloan, and Deborah Schrag

Ethan Basch, Mark G. Kris, Howard I. Scher, Clifford A. Hudis, Paul Sabbatini, Lauren Rogak, Thomas M. Atkinson, Joanne F. Chou, Dorothy Dulko, Laura Sit, Michael Fruscione, and Deborah Schrag, Memorial Sloan Kettering Cancer Center, New York, NY; Ethan Basch, Allison M. Deal, and Antonia V. Bennett, University of North Carolina, Chapel Hill, NC; Amylou C. Dueck, Mayo Clinic, Scottsdale, AZ;

ABSTRACT

Purpose

There is growing interest to enhance symptom monitoring during routine cancer care using patient-reported outcomes, but evidence of impact on clinical outcomes is limited.

Methods

We randomly assigned patients receiving routine outpatient chemotherapy for advanced solid tumors at Memorial Sloan Kettering Cancer Center to report 12 common symptoms via tablet

OBJECTIVES

to test whether systematic web-based collection of PRO, improves HRQL, survival and hospitalization.

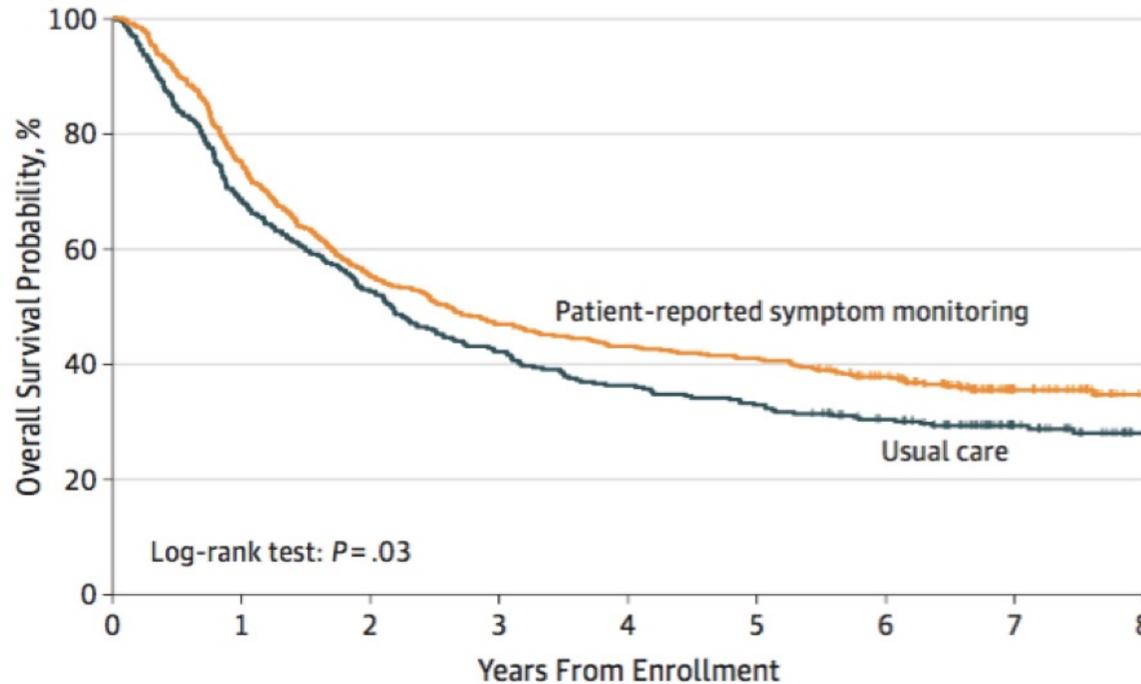
STUDY DESIGN

766 advanced solid tumors, randomly assigned to a
-web-based self-reporting of symptoms
versus
-usual monitoring of care

Basch e, et al., J Clin Oncol. 2016 Feb 20;34(6):557-65



Web-based Symptom Monitoring in Routine Care with Advanced Cancer Patients **improves Survival**



Median OS:
 -PRO Group: **31.2 months**
 -Usual Care Group: **26 months**

No. at risk	0	1	2	3	4	5	6	7	8
Patient-reported symptom monitoring	441	331	244	207	190	181	148	65	33
Usual care	325	223	171	137	118	107	89	50	27

Basch E, et al, JAMA. 2017 Jul 11;318(2):197-198





IL PORTALE DEI PAZIENTI EMATOLOGICI

A cosa serve questo portale



Clicchi qui per vedere un breve video introduttivo sulla piattaforma ALLIANCE



ACCEDI

Nome utente

superadmin

Password

....

Inizia

Cosa può fare nel portale



Rispondere ad alcune domande sul suo stato di salute generale e **monitorare l'andamento dei suoi sintomi** nel corso del tempo

Supporto anche a distanza



Può **condividere** con il suo ematologo informazioni importanti, come **l'andamento dei suoi sintomi**, e trovare nel portale dei suggerimenti per supportarla nel suo percorso

Visite online



Può partecipare alle **visite online** con il suo ematologo





Negli ultimi 7 giorni, quanto è stato grave il senso di **Fatica** o **Stanchezza** al momento peggiore?

Per nulla

Un po'

Abbastanza

Molto

Moltissimo



Results are graphically presented in **real-time** to the physician



CHES

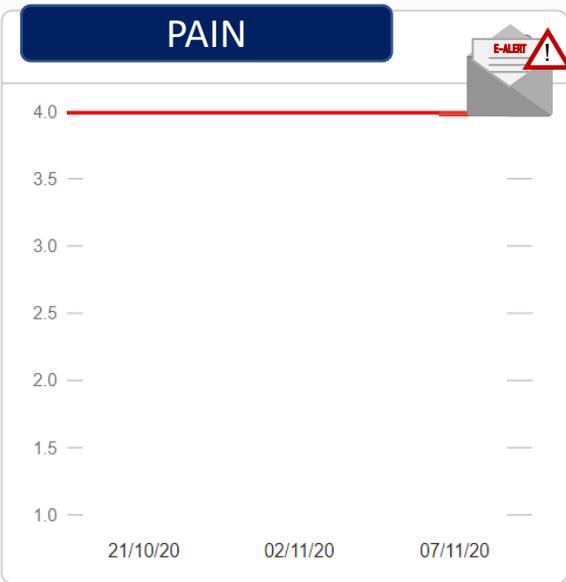
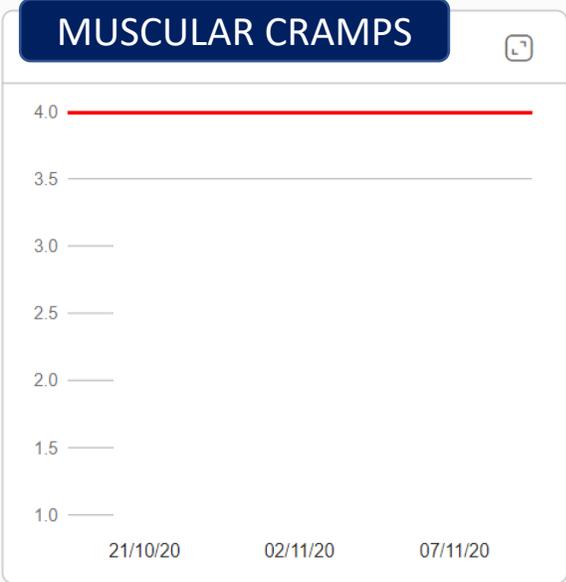
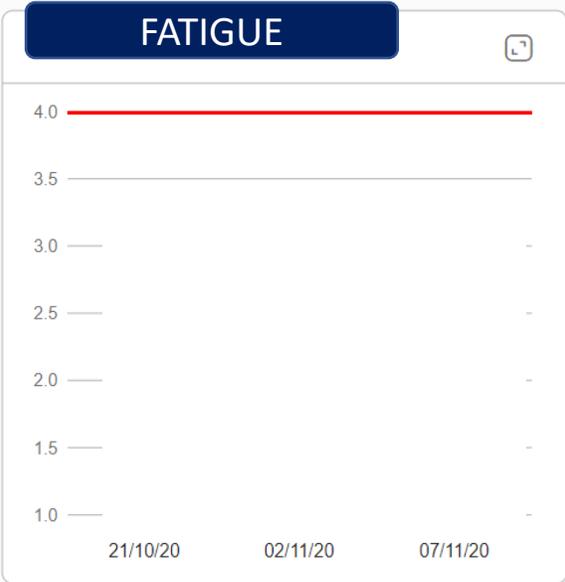
Gestione dei dati ▾ admin ▾

Mario Rossi



Symptom Profile

Print



ONLINE CONSULTATION (module)



0 pazienti parlano con il medico

0 altri pazienti sono in attesa

Il medico **non è presente**





CLINICAL UTILITY AND PHYSICIAN PERCEPTIONS OF A DIGITAL PLATFORM FOR ELECTRONIC PATIENT-REPORTED OUTCOMES MONITORING IN PATIENTS WITH HEMATOLOGIC MALIGNANCIES IN REAL-WORLD PRACTICE



Fabio Efficace¹, Massimo Breccia², Giovanni Caocci³, Leonardo Potenza⁴, Ida Carosino⁵, Francesca Fazio², Maria Teresa Petrucci², Isabella Capodanno⁶, Francesco Cottone¹, Alice Di Rocco², Caterina Patti⁸, Valeria Pioli⁴, Elisabetta Colaci⁴, Davide Giusti⁴, Elisabetta Lugli⁸, Luigi Rigacci⁷, Michela Santopietro⁷, Fulvia Fanelli⁷, Agostino Tafuri⁹, Maria Paola Bianchi⁸, Claudio Carloni², Giusy Antolino⁸, Esmeralda Conte⁹, Edoardo La Sala¹, Massimo Pini⁹, Claudio Fozza¹⁰, Sergio Siragusa¹¹, Marco Santoro¹, Salvatrice Mancuso¹¹, Paolo De Fabritis¹², Nicolina Rita Ardu¹², Pasquale Niscola¹², Andrea Patriarca¹³, Ombretta Annibali¹⁴, Mario Luppi¹⁴, Paola Fazi¹, Marco Vignetti¹

¹Italian Group for Adult Hematologic Diseases (GIMEMA), Data Center and Health Outcomes Research Unit, Rome, Italy; ²Hematology, Department of Translational and Precision Medicine, Azienda Ospedaliera Policlinico Umberto I, Sapienza University of Rome, Rome, Italy; ³Department of Medical Sciences and Public Health, University of Cagliari, Busnaco Hospital, Cagliari, Italy; ⁴Hematology Unit and Chair, Azienda Ospedaliera Universitaria di Modena, Department of Medical and Surgical Sciences, University of Modena and Reggio Emilia, Modena, Italy; ⁵Hematology Unit, Azienda Unità Sanitaria Locale-IRCCS di Reggio Emilia, Reggio Emilia, Italy; ⁶Hematology Unit, Ospedale V. Cervello, Palermo, Italy; ⁷U.O. di Ematologia e Trapianti di cellule Staminali, A.O.S.S. Camillo-Fortanari, Rome, Italy; ⁸Azienda Ospedaliera Sant'Andrea, Rome, Italy; ⁹Hematology and Thrombotic Diseases, San Giovanni Bosco Hospital, Turin, Italy; ¹⁰Department of Medical, Surgical and Experimental Sciences, University of Sassari, Sassari, Italy; ¹¹Policlinico Paolo Giaccone, Unit of Haematology, Department of Health Promotion, Mother and Child Care, Internal Medicine and Medical Specialties (ProMISE) University of Palermo, Palermo, Italy; ¹²Hematology Unit, Sant'Eugenio Hospital, Rome, Italy; ¹³Division of Hematology, Department of Translational Medicine, University of Eastern Piedmont, Novara, Italy; ¹⁴Hematology and Stem Cell Transplantation Unit, University Campus Biomedico, Rome, Italy

INTRODUCTION

There is now great interest in using digital health tools to monitor patients' health status in real-world practice. Such tools often include electronic-patient-reported outcome (ePRO) systems in which symptoms questions are included into online interfaces for patient self-reporting, with real-time alerts triggered to the treating physician if severe symptoms or problems are reported. However, there is little information about the clinical utility and user perceptions of these systems, and this is particularly true in the area of hematology.

METHODS

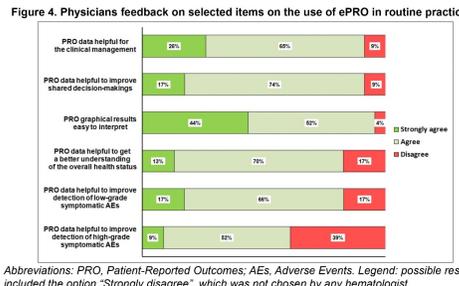
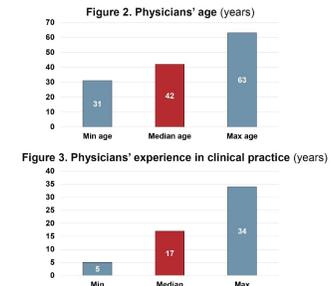
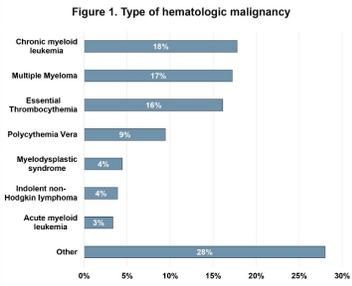
Remote ePROs are being gathered since December 2020 by the ALLIANCE Digital Health Platform, whose details of the development process have been previously described [1]. Adult patients diagnosed with any hematologic malignancy are eligible to enter the platform, after having provided written informed consent. Aspects related to health-related quality of life (HRQoL), symptoms and medication adherence are assessed via validated PRO measures. The platform allows for real-time graphical presentation to physicians of individual patient symptoms and HRQoL outcomes. Based on a pre-defined algorithm, which includes the presence of clinically important problems and symptoms, the platform triggers automated alerts to the treating hematologists and medical staff. The definition of clinically important problems and symptoms is based on previously defined evidence-based thresholds [2]. We asked treating hematologists a feedback about their experience in using the platform, by an ad hoc web-survey consisting of 27 items covering several domains, including: usability and benefits, current use, evaluation of patient health-status, symptoms and adverse events, as well as physician-patient communication. We summarized characteristics of enrolled patients and treating hematologists by proportions, mean, median and range. We also used logistic regression analysis to check the possible association of characteristics of hematologists with survey results.

AIM

This study investigates physicians' perceptions of usability and clinical utility of using remote ePROs in routine practice of patients with hematologic malignancies and explored implications in the delivery of patient care.

RESULTS

Of the 201 patients invited to participate between December 2020 and June 2021 (cut-off date for current analysis), 180 (90%) accepted to enter the ALLIANCE platform, currently activated in 19 centers. The median age of patients was 57 years (range 21-91) and 58% were males. The majority were diagnosed with chronic myeloid leukemia and multiple myeloma (see figure 1) and were in stable disease (n=89, 49%). Twenty-three hematologists (44% males) with a median age of 42 years (figure 2) and an average of 17 years of experience (figure 3) completed the survey. The majority of physicians (78%) accessed the platform at least once per month (of whom 39% at least once per week), regardless the alerts sent by the system about patients' clinically relevant problems. **The frequency of access on a regular basis was also independent of physician sex (p=0.393) and years of experience in clinical practice(p=0.404).** Overall, 57% of hematologists discussed often or very often ePROs with their patients, while 83% and 61% deemed this information helpful to better identify symptomatic adverse events (AEs) of grade 1-2 or of grade 3-4, respectively. Also, 87% and 91% of hematologists found ePROs useful to improve physician-patient communication and the accuracy of documentation of symptomatic AEs (regardless of severity), respectively. Physicians' responses to selected items of the survey are reported in figure 4.



CONCLUSIONS

Current findings support the clinical utility, from the perspective of the treating physician, of integrating ePROs into routine cancer care of patients with hematologic malignancies.

REFERENCES

- 1) Efficace F. et al. The GIMEMA-ALLIANCE Digital Health Platform for Patients With Hematologic Malignancies in the COVID-19 Pandemic and Post-pandemic Era: Protocol for a Multicenter, Prospective, Observational Study. *JMIR Res Protoc.* 2021 Jun 1;10:e25271.
- 2) Giesinger J. et al. Thresholds for clinical importance were established to improve interpretation of the EORTC QLQ-C30 in clinical practice and research. *J Clin Epidemiol.* 2020 Feb;118:1-8

ACKNOWLEDGEMENTS

This study was partly supported by the Associazione Italiana contro le leucemie linfomi e mieloma, Sezione di Roma (ROMAIL "Vanessa Verdecchia" Onlus) and by an unconditional contribution from Abbvie.

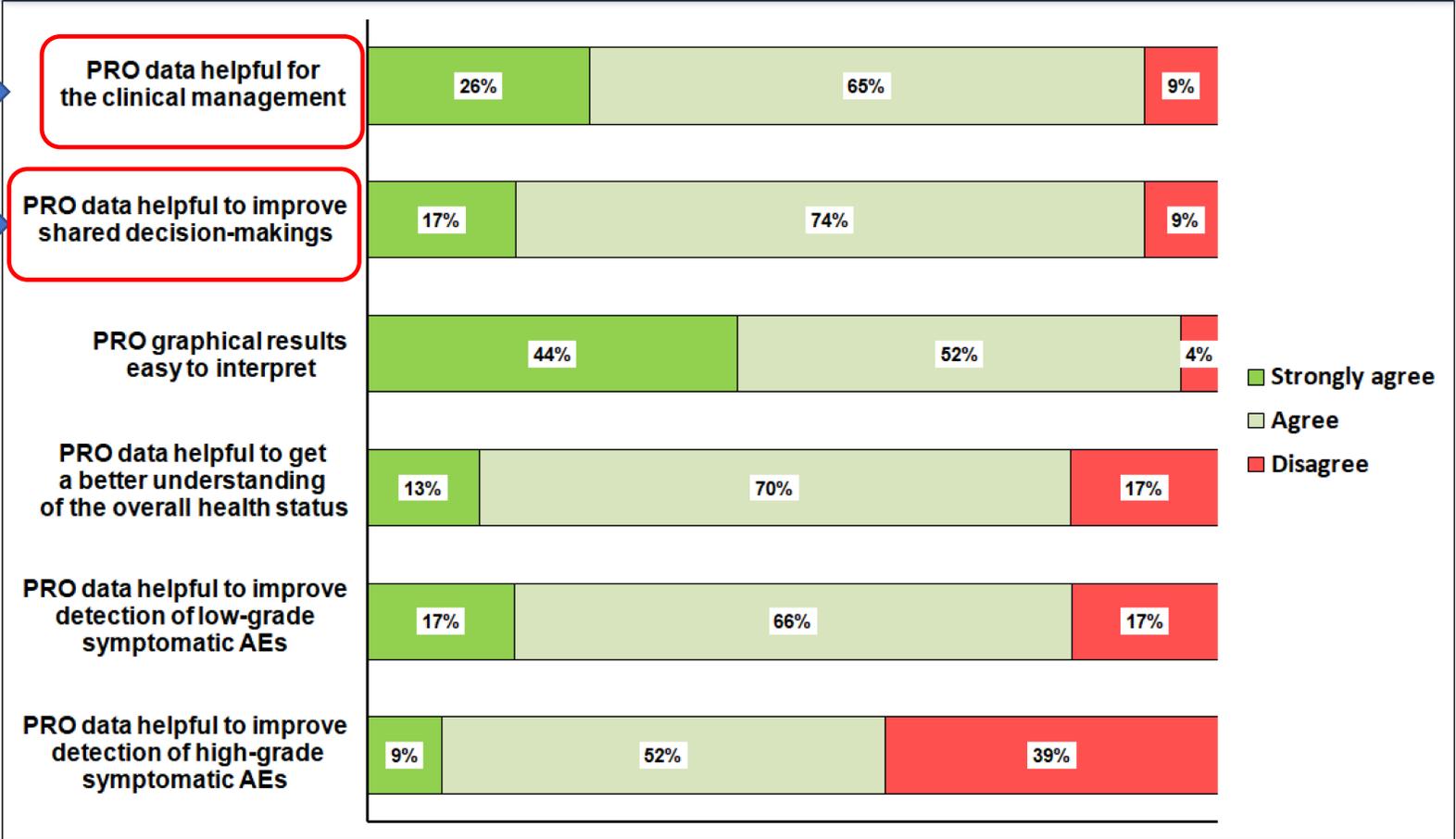
Prof. Fabio Efficace Head, Health Outcomes Research Unit, Italian Group for Adult Hematologic Diseases (GIMEMA). Phone: +39 06 441 639831; E-mail: f.efficace@gimema.it



Physicians Perspective

91%

91%



Abbreviations: PRO, Patient-Reported Outcomes; AEs, Adverse Events.

Legend: possible responses included the option “Strongly disagree”, which was not chosen by any hematologist

Moving towards a more Personalized Approach (1)



1. **ARTIFICIAL INTELLIGENCE/MACHINE LEARNING**
2. **WEARABLES DEVICES**
3. **DIRECT ACCESS TO HOSPITAL MEDICAL RECORDS**



Moving towards a more Personalized Approach (2)

Multiple Myeloma



BONE PAIN

FATIGUE

DYSPNEA

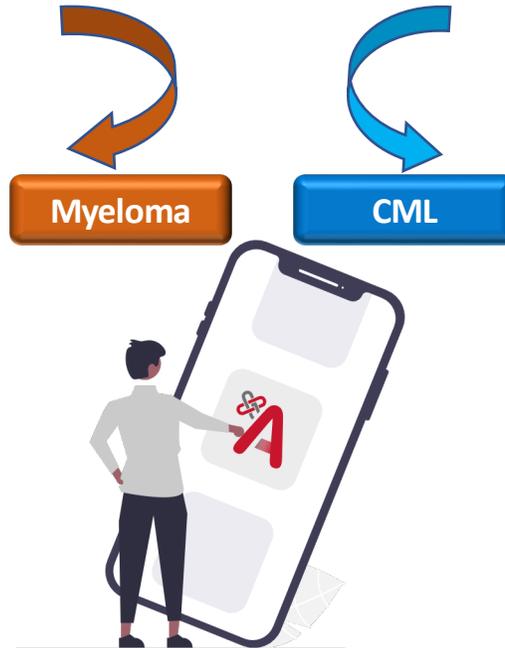
Chronic myeloid leukemia



EDEMA

SKIN RASH

HEADACHE



Conclusions

- **Monitoring Quality of Life (QoL) and Symptoms in routine practice (via Digital Health Tools) is **feasible** and **positively perceived** by patients and their treating haematologists.**
- **A more personalized approach to QoL assessment in routine care can further strengthen the use of Digital tools.**



Acknowledgments



GIMEMA Health Outcomes Research Unit
GIMEMA Working Party on Quality of Life



 **fondazione GIMEMA** onlus
per la promozione e lo sviluppo della ricerca scientifica
sulle malattie ematologiche. **FRANCO MANDELLI**

Paola Fazi
Francesca Tartaglia
Marco Vignetti

 **GIMEMA**
ALLIANCE

 **Roma**
Vanessa Verdecchia · odv
ROMAIL · ASSOCIAZIONE ITALIANA
CONTRO LEUCEMIE - LINFOMI E MIELOMA

